Knowledge, perceptions and attitude of community members and healthcare workers regarding the donation of breast milk and use of donated human milk (DHM) in Empangeni, KwaZulu-Natal

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Declaration

I, Nicole Govender, hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Abstract

Background: Breast milk provides optimal nutrition for infants. Human milk banks allow breast milk feeding for infants who do not have access to their own mother's milk. However, there are variable perceptions and attitudes towards human milk banking.

Aim: This study aimed to evaluate community members' and healthcare workers' knowledge, perceptions and attitudes towards breast milk donation and use in Empangeni, KZN.

Methodology: The research was conducted at a large regional hospital and an affiliated primary health care centre in the area. There were five focus group discussions held with healthcare workers employed at the two sites which explored the attitudes regarding donating and receiving breast milk. In addition, there were sixteen individual semi-structured interviews held with community members. Content analysis was used to analyse the data.

Results and Discussion: Five main themes were found which includes: "Breastfeeding is an optimal feeding choice", "Infant feeding choice", "Misperceptions of HIV", "Knowledge of DHM" and "Acceptance of DHM". Though most participants were aware of breastfeeding benefits, there are poor breastfeeding rates within the area. Many mothers choose to formula feed their infants due to the fear of HIV transmission. There is also a fear of HIV transmission when using DHM. Acceptance of DHM was largely related to knowledge of DHM and exposure to its use.

Conclusion: Healthcare workers need to be given updated, evidence-based information (in accordance with national guidelines and policies) to ensure appropriate counselling of caregivers. Furthermore, community awareness and engagement is required to improve breastfeeding rates and acceptability of DHM.

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Abbreviations and acronyms

ARV- Antiretroviral

BCEA- Basic Conditions of Employment Act

BFHI- Baby Friendly Hospital Initiative

DHM- Donated human milk

DoH- Department of Health

EBM- Expressed breast milk

EPI- Expanded Programme on Immunization

FIO- Facility Information Officer

HIV- Human immunodeficiency virus

HMBANA- Human Milk Banking Association of North America

HMO- Human milk oligosaccharides

IBFAN- International Baby Food Action Network

IYCF- Infant and Young Child Feeding

IQ- Intelligence quotient

KCD- King Cetshwayo District

KMC- Kangaroo Mother Care

KZN- KwaZulu-Natal

LBW- Low birth weight

MBFI- Mother Baby Friendly Initiative

NEC- Necrotising Enterocolitis

NICU- Neonatal Intensive Care Unit

OMM- Own mother's milk

QNRH- Queen Nandi Regional Hospital

PATH- Program for Appropriate Technology in Health

PHC- Primary health care

PIF- Powdered infant formula

PMTCT- Prevention of mother-to-child transmission

SABR- South African Breastmilk Reserve

SADHS- South African Demographic and Health Survey

SAM- Severe Acute Malnutrition

SDG- Sustainable Development Goal

StatsSA- Statistics South Africa

TPN- Total Parenteral Nutrition

UNCRC- United Nations Convention on the Rights of the Child

UNICEF- United Nations Children's Fund

USA- United States of America

VLBW- Very low birth weight

WHA- World Health Assembly

WHO- World Health Organisation

Operational Definitions

Amahewu: A liquid maize meal porridge (Jama *et al*., 2017:11).

Extremely low birth weight: Infants whose weight is <1000g at birth (Cutland *et al*., 2017:6492).

Exclusive breastfeeding: Infant feeding which includes only breast milk for the first 6 months of life. No other liquids or solids are given to the infant except oral rehydration solution or syrups of vitamins, minerals or medicines (WHO, 2019a).

Expressed breast milk: Milk that has been removed from the breast by hand expression or from manual or electric pumping (Becker, Smith & Cooney, 2016:2).

Infant mortality rate: The number of deaths between birth and the first birthday expressed per 1000 live births (Statistics South Africa [Stats SA], 2017:ix).

Low birth weight: Infants whose weight is <2500 grams at birth (UNICEF & WHO, 2004:1).

Mixed feeding: Feeding an infant under the age of 6 months breast milk and other food or liquids (UNICEF, 2005).

Neonatal mortality rate**:** The number of deaths within the first month of life (under 28 days) expressed per 1000 live births (Stats SA, 2017:ix).

Post-neonatal mortality rate**:** The number of deaths after the first month of life but before the first birthday expressed per 1000 live births (Stats SA, 2017:ix).

Under-5 mortality rate: The number of deaths between birth and the fifth birthday expressed per 1000 live births (Stats SA, 2017:ix).

Very low birth weight: Infants whose weight is 1000 to 1499 grams at birth (Cutland *et al*., 2017:6492).

Viral load: The number of HIV ribonucleic acid (RNA) copies per millilitre of blood (United States Department of Health and Human Services, 2019).

Wet nursing: The act of breastfeeding another person's infant (Cambridge Dictionary, 2019).

Chapter one
Introduction

1.1. Background and introduction

Human breast milk is the optimal feeding option for infants (World Health Organization [WHO], 2017). There are several distinctive components which are found in breast milk. According to Andreas, Kampmann & Le-Doare (2015:630-632), lipids are the most abundant energy source in breast milk, supplying 40-55% of total energy. In vitro trials have suggested that the lipids in breast milk have a protective effect against infections at the mucosal surface. They are required for the development of an infant's gastrointestinal tract and central nervous system myelination. In addition, lipids are known to improve the neuro-behavioural development of low birth weight (LBW) infants. Furthermore, there are over 400 different proteins found in breast milk which assist in the absorption of nutrients and also have antimicrobial and immunomodulatory properties. Carbohydrates, which are also present in breast milk are unique where the high lactose content suits the energy requirements of the infant's brain. Human milk oligosaccharides (HMOs) account for a large portion of breast milk carbohydrates and act as prebiotics which stimulate the growth of certain protective bacteria which can prevent diarrhoea and respiratory tract infections. HMOs also play an important role in the immunity, metabolism of infants as well as promoting brain development and cognitive functioning in infants (Victora *et al*., 2016:486).

To ensure optimal health, growth and development of infants, the WHO recommends that mothers exclusively breastfeed infants from birth until six months and thereafter introduce complementary feeds while continuing to breastfeed for 2 years or more (WHO, 2011a). The 2003 South African Demographic and Health Survey (SADHS) (Department of Health [DoH], 2007:143) showed that there are high breastfeeding initiation rates with 83.5% of males and 82.0% of females breastfed within the first day of birth. However, exclusive breastfeeding was not maintained with only 8.3% of infants under the age of six months exclusively breastfed. The 2016 SADHS did not review breastfeeding initiation rates but showed a significant increase in exclusively breastfed infants under the age of six months at 32% (Statistics South Africa [Stats SA], 2017:xiii).

For sick, vulnerable infants in the Neonatal Intensive Care Unit (NICU) and preterm infants who do not have access to their own mother's milk (OMM), the alternative feeding methods are either infant formula or donated human milk (DHM). The Cochrane review comparing formula and DHM feeding of preterm and LBW infants found that there are increased short term weight gain and linear growth rates when infants were fed formula but these infants had a near two-fold increased risk of developing necrotising enterocolitis (NEC) (Quigley, Embleton & McGuire, 2019:17-20). A study conducted in the United States of America (USA) showed that hospitals where DHM was utilised, had increased breastfeeding rates and lower rates of NEC in very low birth weight (VLBW) infants. This suggests improved overall outcomes for VLBW infants in these hospitals (Kantorowska *et al*., 2016:6-7). Therefore, feeding LBW and VLBW infants DHM rather than formula milk is recommended in situations where OMM is not available (WHO, 2011b:3). However, feeding these infants DHM should be a short-term intervention until feeding with OMM is established. Exclusive breastfeeding should be the goal for these infants before they are discharged home (Reimers & Coutsoudis, 2020:2).

Human milk banks are facilities that recruit and screen potential donors to ensure that they are healthy and meet the requirements to donate breast milk. These facilities also process DHM, which includes pasteurisation, quality assurance management and issuing of DHM to preterm infants who require it (KwaZulu-Natal Department of Health [KZN DoH], 2016:5-12).

The Global Strategy for Infant and Young Child Feeding (IYCF) was developed in 2003 by the United Nation Children's Fund (UNICEF) and the WHO. The aim was to highlight the importance of IYCF practices and the effect of these practices on nutritional status, growth and overall health and survival of infants and young children. Breastfeeding was featured as one of the main strategies to promote the health of infants. In situations where breastfeeding is not possible, feeding expressed breast milk (EBM) from an infant's own mother is advised. When OMM is not available, breast milk from a wet nurse or a human milk bank is recommended (WHO, 2003:2-10). In 2008, the World Health Assembly (WHA) reiterated the use of DHM for vulnerable infants, particularly premature and LBW infants (WHO, 2008:30).

Human milk banking is now implemented throughout the world with approximately 550 human milk banks established in more than 37 countries (Program for Appropriate Technology in Health [PATH], 2013:vi; PATH, 2016:1). South Africa highlighted the

strategy of establishing human milk banks in The Tshwane Declaration in 2011 (see chapter 2, 2.3.2. page 15). Subsequently, KZN developed human milk banking guidelines in 2012 to implement throughout institutions in the province (KZN DoH, 2012:3-4).

According to the SADHS 2016, neonatal mortality contributes to approximately half of under-5 deaths in South Africa (Stats SA, 2017:xiii). Increased availability and use of DHM could potentially increase community awareness of the value of breastfeeding, which in turn improves breastfeeding practices and rates (PATH, 2013:5). Improved breast milk feeding rates may contribute to achieving Sustainable Development Goal (SDG) target 3.2 which aims to reduce child mortality by reducing neonatal and post neonatal mortality (United Nations, 2017). Therefore, this research is based on the evidence that by improving the acceptability human milk banks, the collection of DHM can increase thus the availability and use of it for vulnerable infants. The increased availability and short-term use of DHM can improve outcomes of preterm and ill infants who do not have access to their OMM.

1.2. Statement of Research Problem

Queen Nandi Regional Hospital (QNRH), formerly known as Lower Umfolozi Regional War Memorial Hospital is situated in Empangeni in King Cetshwayo district (KCD) which was formerly known as uThungulu district. QNRH is one of the hospitals which the KZN DoH prioritised to establish a human milk bank. The hospital launched a human milk bank in October 2015. The staff working within the neonatal unit have noted that since the establishment of the human milk bank, there are periodic fluctuations in volumes of human milk donated. There are also periods when mothers are reluctant to consent for their infants to receive DHM (Nyawo, personal communication 2019, November 29).

QNRH started collecting DHM in 2013 but lacked the equipment to pasteurise it. To ensure that DHM could be pasteurised, the South African Breastmilk Reserve (SABR) assisted the hospital with pasteurising DHM. This arrangement continued for approximately 18 months. In October 2015, QNRH officially launched the human milk bank when the Sterifeed S90 eco pasteuriser was purchased. Thereafter, training was conducted for nursing staff who were responsible for pasteurising and testing DHM.

Donor recruitment is done within the hospital as many mothers have an extended stay in the Mothers' Lodge when their infants are admitted in the neonatal unit. There is a 92 bedded neonatal unit and the Mothers' Lodge is 82 beds which caters for mothers of both neonatal and paediatric inpatients. In addition, there is a 15 bedded Kangaroo Mother Care (KMC) ward where mothers are able to room in with their infants. There are periodic fluctuations in number of donors recruited and DHM collected as represented in Table 1 below over a 12 month period in 2018. There are variations between mothers screened and actual donors as some mothers may have not met the inclusion criteria to donate breast milk. It has been observed that mothers often influence each other regarding breast milk donation whilst their infants are admitted in the neonatal unit and the institution often has long periods where mothers do not want to donate their breast milk. Contrarily, there are times when there is a surplus of donor mothers who are willing to donate their breast milk. This is a trend that the researcher as well as staff working within the unit have observed.

Table 1: Table showing QNRH human milk bank statistics in 2018 (QNRH statistics)

	Jan	Feb	March	April	May	June	July	Aug	Sept	Oct	Nov	Dec
Number of mothers screened	27	30	18	26	30	20	33	32	38	10	28	30
Number of new donors	25	22	14	14	19	10	19	13	22	4	15	17
Volume DHM collected (ml)	18 011	17 464	9890	10 465	12 300	11 965	6905	6090	5590	3290	8656	18 458
Volume DHM dispensed (ml)	10 531	8438	14 383	22 014	9947	2670	12 819	5127	9803	9762	1685	6061
Number of new infants given DHM	18	18	20	25	24	11	18	20	22	14	2	15
Volume pasteurized (ml)	19 575	12 980	15 325	9970	14 535	11 627	6800	7090	3950	5560	7880	7938

Variable perceptions and attitudes towards human milk banking could contribute to fluctuating breast milk donation and acceptance of DHM. There is limited understanding of the knowledge, attitudes and perceptions of healthcare workers and community members regarding the donation of breast milk and use of DHM in Empangeni.

1.3. Study Setting

It has been estimated that in 2015, there were almost 7 million people infected with HIV in South Africa. KZN is known to have the highest prevalence of antenatal HIV in the country with approximately 44.4% of pregnant women living with HIV. In addition, KCD has an antenatal HIV prevalence of 45.9% (DoH, 2017:2-36).

In addition to the high prevalence of HIV, KZN is also known to have the highest infant mortality rate (IMR) in the country with an estimated 31 infant deaths per 1000 live births and under-5 mortality rate of 42/1000 in 2016/2017 (KZN DoH, 2017:113). Neonatal deaths (preterm birth complications, birth asphyxia and sepsis) contributes to 28.1% of under-5 mortality (Msemburi *et al*., 2016:8).

The 2017/2018 national target for "Infants exclusively breastfed at DTaP-IPVHib-HBV 3rd dose rate" (14 weeks in EPI schedule) was 52% with the actual national rate 47.8% for that time period. There is a higher exclusive breastfeeding rate within KCD with 58.5% of infants reported to be exclusively breastfed at 14 weeks (Massyn, Pillay & Padarath, 2019:114-116).

The province of KZN has 11 districts. KCD is situated in the northern area of KZN and is comprised of 5 local municipalities. KCD, with a population size of approximately 900 000 is the third most populous district in the province. It is estimated that 80% of the population reside in rural areas. There is a high rate of malnutrition, tuberculosis and HIV in the district. There is also a high unemployment rate of 34.7%. Access to electricity is an important social determinant of health and only 75.8% of households have access to electricity within the district (KCD, 2018:11-17). Empangeni is one of the most densely populated towns located within the City of Umhlathuze and has an estimated population of over 110 000 (Wikipedia, 2019).

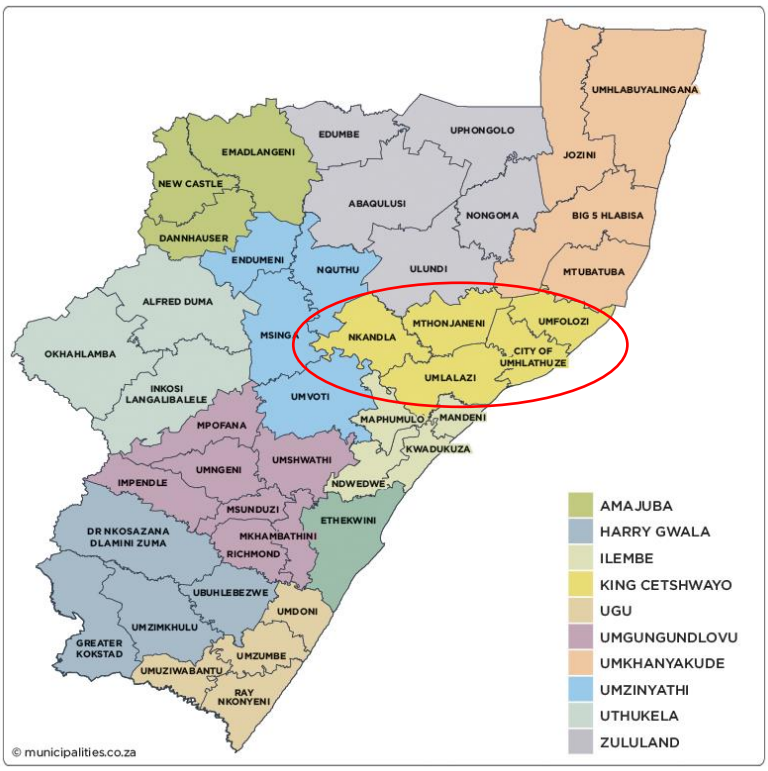

Figure 1: Geographical location of King Cetshwayo district in KZN (Municipalities of South Africa, 2019)

Two sites were purposively selected for the study. Firstly, QNRH is a Mother Baby Friendly Initiative (MBFI) accredited regional maternity and paediatric hospital located in Empangeni, KZN and is a referral centre for KCD, uMkhanyakude and Zululand districts. The hospital provides obstetric, gynaecological, neonatal and paediatric services (KZN DoH, 2018a). According to the hospital's Facility Information Officer (FIO), in the year 2018, there were 8239 deliveries with more than 50% as caesarean sections. The total number of LBW infants delivered was 1679 making the LBW rate 20.5/1000. The 92 bedded neonatal unit had 3591 admissions in 2018 (Makhoba, personal communication 2019, January 31). The neonatal unit clinical manager noted that the birth weight categories on admission are as follows: 123 admissions <1000g, 380 admissions 1000-1499 g, 956 admissions 1500-2499 g and the remainder normal birth weight or large for gestational age infants (Gasarasi, personal communication 2019, January 31). There are currently no data available on NEC rates within the unit. The hospital was chosen for the study as many staff members have received training in human milk banking and DHM is collected, processed and dispensed there.

Empangeni clinic is a local primary health care (PHC) facility which is also located in Empangeni. The clinic is not MBFI accredited. This PHC facility was chosen as staff members have not been trained on human milk banking and it is important to gain information on their attitudes and perceptions of collecting DHM. PHC facilities need to increase awareness about human milk banking to advocate for recruitment of donors outside the hospital. This could assist in meeting the increased demand for DHM. Empangeni clinic was also chosen as it is easily accessible for the researcher in comparison to other PHC facilities which are situated in rural areas with poorly maintained roads and a high crime rate. The lack of data from deep rural areas is a weakness of the study.

1.4. Study participants

The study will involve staff members employed at QNRH and Empangeni clinic. Community members attending these facilities will also be recruited as participants. There are very few non- South Africans living within the area. Inclusion criteria include participants over the age of 18 who can speak IsiZulu or English. Exclusion criteria exclude any mothers with post-partum psychosis as well as participants who cannot speak IsiZulu or English. Inclusion and exclusion criteria is explained in greater detail in Chapter 3 (see 3.6. pg 23).

1.5. Rationale

There is research related to the efficacy of DHM feeding (compared to infant formula) when OMM is not available (Quigley, Embleton & McGuire, 2019:20). However, there are limited data on perceptions and attitudes of health care workers and community members to both donating breast milk and receiving DHM in rural settings in KZN (Coutsoudis, Petrites & Coutsoudis, 2011:1-2). Advocacy for breastfeeding and human milk banking within the community is required to improve awareness and acceptability of human milk banking (Goodfellow *et al*., 2016:85).

This study is intended to explore contextual factors, knowledge, attitudes and perceptions of healthcare staff and community members about milk banking in Empangeni, KZN. By creating a reflective space in which staff and community members can share their perceptions, practices, understanding and attitudes about human milk banks, potential challenges related to the introduction and operation of human milk banks can be identified. Due to fluctuations in

the number of donors recruited and DHM collected, the research will examine the factors which may influence this, including factors which may impact acceptance of human milk banking.

The findings could potentially improve current practices and possibly provide information to implement a quality improvement plan within the facilities or province and possibly improve the implementation of human milk banking. The results of the study will be shared with the KZN DoH.

1.6. Aim of the Study

The aim of the study is to evaluate community members' and healthcare workers' knowledge, perceptions and attitudes towards breast milk donation and use in Empangeni, KZN.

1.7. Research Question

To determine the knowledge, perceptions and attitude of community members and healthcare workers regarding the donation of breast milk and use of DHM in Empangeni, KZN.

1.8. Specific Objectives

1. To investigate community members' and healthcare workers' perceptions, attitudes and acceptance of DHM in Empangeni.
2. To identify contextual factors about human milk banks within the area.
3. Identify challenges in collecting DHM from the community and primary health care facility.
4. To provide staff members with a forum to discuss challenges relating to DHM collection and use.
5. To provide the KZN DoH with findings regarding DHM collection and use in Empangeni.

1.9. Summary

This chapter included a brief background in breastfeeding and human milk banks. The study setting was discussed and highlighted the need for more research required about knowledge, attitudes and perceptions of DHM in Empangeni, KZN. In addition, the study aim and objectives were identified.

Chapter Two
Literature Review

2.1. Introduction

Chapter one included an introduction and background to breastfeeding and the importance of human milk banking, a brief description of the study setting and the aim and objectives of the research. Chapter two is a review of relevant literature related to breastfeeding which includes the benefits of breastfeeding, the international guidelines and policies to support breastfeeding and the strategies in South Africa to improve breastfeeding rates. In addition, feeding of preterm infants, the importance of human milk banking in the management of sick, vulnerable infants and the effect of human milk banking on breastfeeding rates is discussed. Furthermore, data on healthcare workers' and community members' perceptions and attitudes towards human milk banking is reviewed.

2.2. Benefits of breastfeeding

Breastfeeding is the optimal feeding method for infants because of its superior nutritional and disease prevention qualities (WHO, 2011a). Breastfeeding has a significant impact on morbidity and mortality of both children and mothers. It has been estimated that improving breastfeeding rates to near universal levels (95% in infants younger than 6 months and 90% in the age category 6-23 months) can prevent approximately 823 000 childhood deaths annually which is equivalent to 13.8% of the under-5year deaths (Victora *et al*., 2016:485-487). Breastfeeding is the most cost-effective intervention to prevent childhood deaths as it is easily available at household level and is most affordable when compared with other strategies such as supplementation of Vitamin A and Zinc. Estimated deaths prevented by various interventions is represented in Figure 2 below (Jones *et al*., 2003:69).

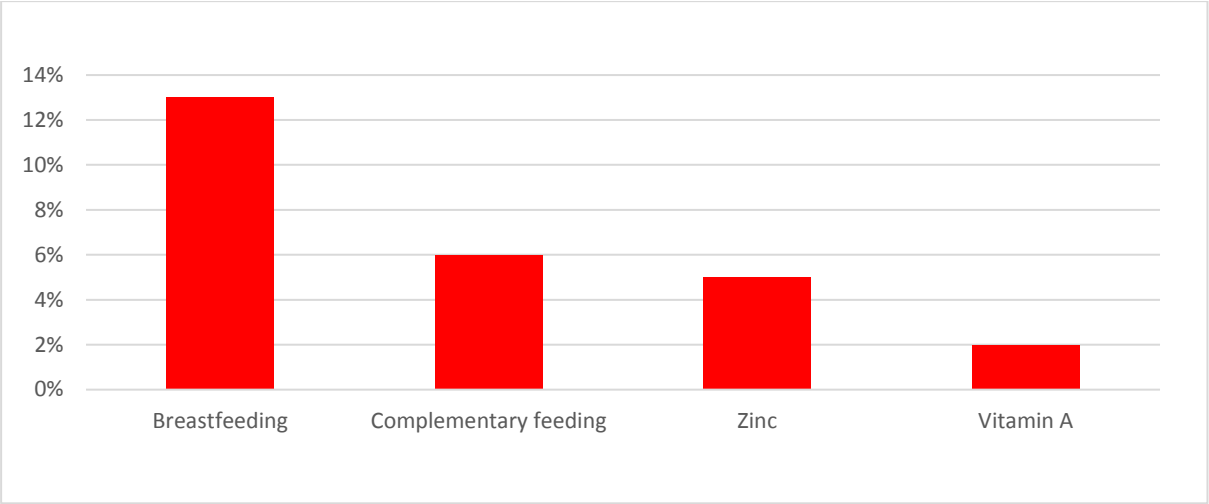

Figure 2: Estimated under-5 deaths prevented from various interventions (adapted from Jones *et al*., 2003:67)

In addition, breastfeeding has a protective effect against breast cancer (and possibly ovarian cancer) for nursing mothers where an estimated 20 000 deaths from breast cancer can be prevented annually (Victora *et al*., 2016:475-488).

There are short and long term benefits for breastfed infants. Breast milk contains immunoglobulins and other substances which have a protective effect against infections which is particularly beneficial whilst infants' immune systems mature (Andreas, Kampmann & Le-Doare, 2015:631). Preterm infants fed more than 50% of total feeds as OMM in the first 14 days of life have an 83% risk reduction of NEC compared to those receiving less than 50% of total feeds as OMM. In addition, intake of OMM is associated with a 50% lower rate of neonatal sepsis (Maffei & Schanler, 2017:37). In cases where OMM is not available, use of DHM rather than infant formula feeding may have a protective effect against development of NEC in preterm and LBW infants (Quigley, Embleton & McGuire, 2019:20).

Breastfeeding also provides protection from respiratory infections with a third of respiratory infections and 57% of hospital admissions for respiratory infections being preventable if infants are breastfed (Victora *et al*., 2016:479). Furthermore, a Systematic Review conducted by Horta and Victora (2013:1-2) showed that breastfeeding reduces the risk of developing diarrhoea by half and of hospital admissions for diarrhoea by 72%. In addition, diarrhoea mortality was 77% lower in breastfed infants.

According to Brahm and Valdes (2017:17), breastfeeding is also associated with several long term benefits such as a reduced risk of developing non-communicable diseases in adulthood with 15-30% less risk of breastfed infants becoming obese adolescents and adults. However, confounding factors should be considered when reviewing study design and results of trials. According to Kramer *et al*. (2009:419S), a randomized controlled trial was conducted in Belarus and showed no statistical significant effect of exclusive breastfeeding and longer duration of breastfeeding on childhood overweight and obesity.

Breastfeeding has a possible protective effect against the development of Type 1 Diabetes and decreases the risk of developing Type 2 Diabetes in breastfed infants (Brahm & Valdes, 2017:17). Moreover, a meta-analysis conducted by Horta, de Mola & Victora (2015:16), has shown that breastfeeding is associated with a higher intelligence quotient (IQ) in children and adolescents.

2.3. Policies and guidelines to support breastfeeding

2.3.1. Global policies and guidelines to support breastfeeding

Due to the numerous benefits of breastfeeding for children and their mothers, there are global policies and guidelines which support breastfeeding. Firstly, the United Nations Convention on the Rights of the Child (UNCRC) stipulates basic rights for children including their right to survival, protection and development in article 6. Article 24 includes children's right to health which includes optimal nutrition as well as parents having access to education regarding the benefits of breastfeeding (United Nations, 1989). Breastfeeding is instrumental in protecting and fulfilling these rights by preventing morbidity and mortality of children as well as providing optimal nutrition (International Baby Food Action Network [IBFAN], 2). Therefore, the protection, promotion and support of breastfeeding is crucial in ensuring food security, optimising health and development, and reducing child mortality (UNICEF, 2015:18).

During the 1970's the WHA highlighted the decrease in breastfeeding rates and the necessity to regulate marketing of breast-milk substitutes in an effort to protect breastfeeding. In 1981, the final version of The International Code of Marketing of Breast-milk Substitutes was developed and adopted by the Member States of the WHO. The aim of the Code is to protect

and promote breastfeeding by preventing inappropriate marketing of infant formula, complementary feeds, and feeding bottles and teats (WHO, 1981:4-8). In 1990, the Innocenti Declaration on the Protection, Promotion and Support of Breastfeeding set four operational targets, namely specifying that all countries should appoint a national breastfeeding coordinator, encourage facilities to adopt the "10 steps to successful breastfeeding", highlight the importance of abiding by the International Code of Marketing of Breast-milk Substitutes and to protect breastfeeding rights for working women (UNICEF, 1990). A further effort by the WHO and UNICEF to protect, promote and support breastfeeding was the launch of the Baby Friendly Hospital Initiative (BFHI) in 1991 which has been implemented in healthcare facilities throughout the world to improve breastfeeding rates (WHO, 2019b). In addition, the Global Strategy for IYCF was developed in 2003 where again the importance of breastfeeding was emphasised (WHO, 2003:2).

Breastfeeding plays a pivotal role in achieving all the SDGs. Breastfeeding can help countries reach SDG goal two which is zero hunger where breast milk provides optimal nutrition for infants. SDG goal three is good health and well-being which can be attained for infants and young children through breastfeeding. In addition, breastfeeding practices can help to promote quality education as well as gender equality which are included in SDG four and five (United Nations, 2017).

In situations when OMM is not available, the WHO recommends that vulnerable infants, particularly LBW and preterm infants are fed DHM (WHO, 2008:30). The WHO hierarchy of feeding choices for LBW infants is represented in Figure 3 below. This recommendation is also supported by the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) (Arslanoglu *et al*., 2013a:540). Furthermore, the American Academy of Paediatrics (AAP) advocates for the use of DHM for both preterm and term infants (Eidelman & Schanler, 2012:e831-e835). Benefits of DHM feeding (when OMM is not available) in preterm and VLBW infants, include decreased risk of development of NEC and improved feed tolerance (Arslanoglu *et al*., 2013a:536; Quigley, Embleton & McGuire, 2019:20). In addition to benefits for the recipients of DHM, the presence of human milk banks may also contribute to increased breastfeeding rates on discharge by creating a culture of breastfeeding in NICUs (Arslanoglu *et al*., 2013b:130-131).

However, as a scarce resource, DHM is usually reserved for use in VLBW infants. There are few data on the use of DHM in vulnerable term infants and older infants who do not have access to OMM (Reimers *et al*., 2018:1).

Figure 3: WHO hierarchy of feeding choices for LBW infants (PATH, 2013:1)

2.3.2. Policies and strategies to improve breastfeeding rates in South Africa

The UNCRC is reiterated in the South African Bill of Rights. Section 27 states that everyone has the right to adequate food and section 28 highlights children's rights to basic nutrition which can be fulfilled by breastfeeding (Constitution of the Republic of South Africa, Section 27 & 28, 1996:11). In order to protect children's human rights in South Africa, breastfeeding must be prioritised. The Basic Conditions of Employment Act (BCEA) stipulates that breastfeeding employees are allowed to have two thirty minute breaks to breastfeed or express breast milk for their infants per day until the infant is six months of age (Basic Conditions of Employment Act, No. R. 1441, 1998).

Millennium Development Goal four was to reduce under-5 child mortality by two thirds. In 2011, the country's under-5 mortality rate and IMR were still high at 38.7/1000 (target

20/1000) and 26.5/1000 (target 18/1000) respectively and not on track to meet the targets (StatsSA, 2015:10-11). The high IMR in relation to extremely low exclusive breastfeeding and extended breastfeeding rates motivated a National Breastfeeding Consultative Meeting in South Africa in 2011. At this meeting, the Minister of Health with other stakeholder groups discussed the challenges related to poor breastfeeding practices. The resulting Tshwane Declaration prioritised promoting, protecting and supporting breastfeeding to decrease child morbidity and mortality. South Africa decided to implement the 2010 WHO guidelines on HIV and infant feeding which recommends that all mothers with HIV should breastfeed their infants with antiretroviral (ARV) drug cover to prevent transmission of HIV. The previous policy included the distribution of free formula for many HIV positive mothers. The revised guidelines stopped the dispensing of free formula at public health facilities unless there was a medical indication. In addition, it included a statement on the role of Human Milk Banking: "Human milk banks are promoted and supported as an effective approach, especially in post-natal wards and neonatal intensive care units, to reduce neonatal and post-neonatal morbidity and mortality for infants who cannot breastfeed" (DoH, 2010:33; DoH, 2011:214).

There were several other important outcomes of this meeting. In 2013, the National IYCF Policy was also revised to promote and support breastfeeding within the country, especially in the context of HIV. The establishment of human milk banks was highlighted in the policy to prioritise high risk infants who do not have access to OMM (DoH, 2013:22). Furthermore, the National IYCF Policy was amended in 2017 to align with the WHO 2016 recommendation that the duration of breastfeeding HIV-exposed infants be increased from 12 to 24 months whilst supporting ARV adherence (KZN DoH, 2018b:1).

South Africa adopted the BFHI in healthcare facilities in 1994. In 2011 South Africa amended the programme by adding three additional items to the original 10 steps of the BFHI which is now known as the MBFI. MBFI emphasised compliance to the International Code of Marketing of Breast-milk Substitutes, infant feeding in the context of HIV and promoting mother friendly care (Martin-Wiesner, 2018:16). The steps are shown in Figure 4 below. However, human milk banking is not featured directly in the steps.

MBFI

10 steps

1. Have a written breastfeeding/IYCF policy that is routinely communicated to all health care staff.
2. Train all health care staff in skills necessary to implement this policy.
3. Inform all pregnant women about the benefits and management of breastfeeding.
4. Help mothers initiate breastfeeding within an hour of birth and practise skin to skin for an hour unhurried.
5. Show mothers how to breastfeed, and how to maintain lactation even if they should be separated from their infants.
6. Give new born infants no food or drink other than breast milk, unless medically indicated.
7. Practise rooming-in – that is, allow mother and infant to remain together 24 hours per day.
8. Encourage breastfeeding on demand.
9. Give no artificial teats or pacifiers (also called dummies or soothers) to breastfeeding infants.
10. Foster the establishment of breastfeeding support groups and refer mothers to them on discharge from the hospital or clinic.

Three Additional Items:

1. Compliance to the International Code of Marketing of Breast-milk Substitutes.
2. Infant feeding in the context of HIV.
3. Promoting mother friendly care.

Figure 4: The 10 steps to successful breastfeeding and 3 additional items (adapted from Martin-Wiesner, 2018:16)

The National Development Plan was launched in 2012 and featured "the first 1000 days" which refers to the time from conception until a child's second birthday (National Planning Commission, 2012:379). Optimal nutrition and care during this period is important for survival, health and quality of life. Breastfeeding is crucial during the first six months of life

as it is the "first immunisation" which protects infants against illnesses and death (UNICEF, 2017:1-2). Breastfeeding is one of the first early childhood development interventions in which it provides all the nutrients required for optimal brain development and is associated with a higher IQ in children and adolescents. This could assist children with good academic performance as well as better work opportunities during adulthood (UNICEF, 2016:2-3). Therefore, breastfeeding ensures optimal mental, psychological and emotional health of infants and plays a pivotal role in the country's development (du Plessis *et al*., 2016:111).

In addition, National Regulations on Human Milk Banking were drafted as the scaling up of human milk banks is one of the initiatives to promote breast milk feeding in new born infants, especially preterm infants (*National Health Act, No. 61 of 2003. Regulations, as amended,* 2015:6). In 2016, the KZN DoH updated the provincial Human Milk Banking guidelines. Furthermore, the National Human Milk Banking Guidelines are currently being finalised (KZN DoH, 2016:3).

2.4. Use of formula milk

Despite breastfeeding being the optimal infant feeding choice, many mothers still choose to feed their infants formula which may be due to reasons such as poor breastfeeding knowledge and education as well as mothers' perception that they have insufficient breast milk supply to meet their infant's requirements (du Plessis, 2013:5). The frequently changing infant feeding recommendations of the HIV Prevention of Mother to Child Transmission (PMTCT) programme from avoidance of breastfeeding and issuing of free infant formula to the post Tshwane Declaration policy of breastfeeding with ARV cover also caused confusion for caregivers and healthcare providers regarding infant feeding in the context of HIV. In addition, state subsidised infant formula may have resulted in HIV negative mothers regarding formula feeding as a safe infant feeding method. Moreover, community dialogues conducted in KZN showed that community members and elders, specifically grandmothers have an influence on infant feeding decisions (du Plessis *et al*., 2016:111-112).

Formula milk is a suboptimal feeding method for infants, specifically preterm infants. Infant formula is of a much poorer nutritional quality and lacks the protective properties that is contained in breast milk (Andreas, Kampmann & Le-Doare, 2015:630-631). In addition, powdered infant formula (PIF) could be contaminated from intrinsic and extrinsic sources.

PIF could be contaminated during the manufacturing process and there may be substandard hygiene practices when preparing formula feeds which puts infants at a high risk of infection (WHO, 2007:4). There is also an increased risk of developing NEC, an increased duration of use of Total Parenteral Nutrition (TPN), as well as higher rates of sepsis in preterm infants who have been fed formula milk (Hay Jr & Hendrickson, 2017:20).

2.5. Feeding of premature infants

Preterm infants are most susceptible to the development of NEC. Their immature gastrointestinal tract causes them to have less "gastric proteolytic enzymes, increased gastric pH, decreased intestinal motility, increased intestinal permeability, altered epithelial membrane tight junctions, and diminished intestinal mucus coat". These factors cause preterm infants to have difficulty in digesting and absorbing complete cow's milk protein and contribute to development of NEC and highlight the importance of breast milk feeding in this group (Maffei & Schanler, 2017:37-38). Mothers of preterm infants are required to start expressing breast milk for each feed soon after birth as these infants are not yet able to suckle on the breast and will require feeding via nasogastric tube, syringe or cup. EBM may be needed for several weeks until the infant can suckle effectively from the breast. However, these mothers have various challenges with breast milk expression including poor milk production due to the delivery before term, separation or complications during the perinatal period such as caesarean delivery, eclampsia, other maternal illness or even admission to intensive care. There may also be poor support for mothers to breastfeed post-delivery (Bonet *et al*., 2015:2). In addition, in some cases there may be maternal deaths. Consequently, some vulnerable infants may not always have access to their OMM (Taylor *et al*., 2018:1-3). The WHO (2011b:3) strongly recommends feeding LBW infants DHM rather than infant formula in situations where OMM is not available as seen in Figure 3.

2.6. Perceptions and attitudes towards human milk banking

2.6.1. Perceptions and attitudes of community members

There have been various studies conducted throughout the world which evaluate perceptions and attitudes towards human milk banking. A study conducted in the USA included interviewing post-partum mothers who were rooming in and giving supplemental feeds to

their healthy infants. Mothers chose to give either DHM or formula in addition to breastfeeding. The following main themes were identified: firstly, that formula supplementation was an easily available resource and could be a longer term feeding option rather than DHM which would not always be available. In addition, many mothers assumed that DHM would be expensive because in the USA, caregivers have to pay for DHM on discharge. A few mothers also felt that the concept of using DHM is foreign and unfamiliar. Most mothers who chose DHM as supplemental feeds noted that DHM was chosen due to the health benefits for the infant (Kair & Flaherman, 2017:711-713).

Research conducted in a NICU in the USA by Esquerra-Zwiers *et al*. (2016:97-99) showed that mothers who consent for their infants to receive DHM often had insufficient breast milk and felt that providing consent for their infants to receive DHM was in their infants best interest. However, these mothers expressed that they did not always feel comfortable with feeding their infants with someone else's breast milk and wished that they could supply sufficient OMM. Contrary to this, several mothers provided consent because they were concerned about the safety of their own breast milk and did not want to breastfeed. Furthermore, some participants were concerned about the safety and quality of DHM due to not having knowledge about donor screening and processing of DHM.

Brownell *et al*. (2014:396) investigated patterns and predictors of caregivers not consenting to give their infants DHM and found two main predictors. This included race and marital status. It was found that within the study setting (a NICU within the USA), mostly black and other non- white mothers did not consent to DHM. Culture may play a role in acceptability of use of DHM due to different cultural beliefs. In addition, marriage was also a risk factor for non-consent of DHM.

A study conducted in KZN reviewing perceptions of community-based human milk banks showed that many caregivers were concerned about the safety of giving DHM to their infants. These caregivers received breastfeeding peer counselling training and once they had received training on community-based human milk banking, they found it more acceptable to donate their breast milk as well as feed their own infants DHM. Limitations of this study include that only women who could speak English were interviewed and trained, only mothers and not other community members were interviewed and the study was conducted within a more urbanised area and may not be reflective of rural areas in KZN. It was emphasised that

breastfeeding promotion should target communities. This should include partners, grandparents and community leaders as there are several myths regarding DHM which should be identified and discussed (Goodfellow *et al*., 2016:83-85). The fear of HIV transmission may also impact the acceptability of donating breast milk or mothers consenting to their infants receiving DHM (Coutsoudis, Petrites & Coutsoudis, 2011:2).

Iloh *et al*. (2018:5-11) showed that most participants in a study investigating mothers perceptions of DHM in Nigeria, had not heard of the concept of human milk banking. Out of the participants who were aware of human milk banking, 46% had obtained information from healthcare workers. A limitation of this research is that it did not include health care providers or community members who are the influencers in breast milk donation. In addition, research in Brazil investigating the factors affecting breast milk donation showed that healthcare professionals were most influential on donors deciding to donate breast milk as well as donors being receptive to the needs of vulnerable infants within the neonatal unit and wanting to help these infants (Thomaz *et al*., 2008:74-76).

The research conducted by Iloh *et al*. (2018:11) also showed that some mothers required compensation for donating milk in the form of financial remuneration. However, mothers not requiring compensation were more willing to donate breast milk.

Religion also plays a role in acceptability of the use of DHM. Within Muslim communities there is a belief that accepting DHM creates a "kinship" between the donor and her children with the recipient of DHM. The donor's children and the recipients are then known to be "milk siblings" and are therefore not allowed to marry each other (Ergin & Uzun, 2018:455). Muslim communities are generally more accepting of DHM if the donor is known to the family of the recipient (Al-Naqeeb *et al*., 2000:346).

2.6.2. Perceptions and attitudes of healthcare workers

A study in Australia reviewed NICU nursing staff and doctors attitudes and knowledge regarding human milk banking. It was found that the majority of these healthcare professionals thought that DHM was superior to formula, specifically in feeding preterm infants though fewer participants felt that DHM was the preferred feeding option for term infants. In addition, the results indicated that nurses have a greater acceptance for DHM than

doctors. However, there was a significantly larger percentage of male doctors who took part in the study which could also suggest that gender may play a role in attitudes and knowledge towards milk banking (Lam, Keckés & Abdel-Latif, 2012:835-836).

According to Lubbe *et al.* (2019:7), healthcare professionals in the North West province of South Africa noted that there needs to be more awareness regarding human milk banking as well as remuneration for donors to improve acceptability of the practice.

2.9. Conclusion

Breastfeeding is an effective nutrition intervention for all infants to improve health and decrease child morbidity and mortality. There are numerous global policies and guidelines that have been established to promote and protect breastfeeding. South Africa has also made several efforts to improve breastfeeding rates including promoting establishment of breast milk banks. Breast milk is crucial for the management of preterm infants and in cases where OMM is not available, the use of DHM is strongly recommended. However, there are challenges with perceptions and attitudes towards donating breast milk and receiving DHM. In addition, there is a paucity of data in rural areas of KZN with limited research investigating perceptions and attitudes towards breastfeeding and human milk banking.

This research aims to explore the knowledge, attitudes and perceptions of human milk banking of community members and health care workers in Empangeni, KZN and to identify possible challenges in milk bank implementation.

Chapter three
Methodology

3.1. Introduction

Chapter two reviewed the relevant research related to breastfeeding and human milk banking and highlighted the need for more research in the area of knowledge, perceptions and attitudes towards human milk banking. Chapter three will include an explanation of the methodology used in the study.

3.2. Study design

A cross sectional study was conducted by means of semi-structured interviews and focus group discussions. A qualitative approach was chosen as it provides new information regarding behaviour and social processes (Skinner, 2014:349-351). A qualitative study design is suitable for this study as it relates to the objectives of the research study which includes determining healthcare workers and community members' knowledge, attitudes and perceptions of human milk banking.

3.3. Study population

The target population from which the study sample was selected were healthcare workers which included nursing staff and doctors working in maternity or paediatric wards as well as nutrition advisors. In addition, other stakeholders such as hospital management were invited to participate in the study. The other target group was community members which included pregnant women, mothers and other primary caregivers who attend either QNRH or Empangeni clinic for healthcare services.

3.4. Sampling

To ensure that data was collected from a variety of important stakeholders, healthcare staff working with mothers and children and community members were included. Interviewing both groups at QNRH and Empangeni clinic ensured that there were two sites for data collection. Homogenous sampling was used as a technique of purposive sampling to ensure

that participants meet the inclusion criteria (Ulin, Robinson & Tolley, 2005:57). This was done to ensure that the researcher chose a sample that will incorporate a variety of characteristics (Skinner, 2014:354). Sampling was done in February and March 2019. Sixteen community members were chosen to participate in the interviews. Two of which were part of the pilot study and were not included in the final number of participants. In addition, five focus groups were conducted with six healthcare workers per group. One of the focus groups was part of the pilot study but included valuable data which will be included in the study findings. Therefore, there were 44 participants in total. The final number of participants was based on data saturation when no new themes were found.

3.5. Participant recruitment

The researcher discussed the study in advance with QNRH and Empangeni clinic management. The management teams were asked to be involved in the research as well as give permission to other stakeholders to participate. Hard copies of the advertisement of the study were pasted on the walls with the contact number of the researcher. Participants were recruited by approaching community members who attend Empangeni clinic or QNRH to utilise maternity or paediatric services. This includes outpatient services and caregivers whose children were admitted in the neonatal or paediatric wards. Staff members recruited included nursing staff and one nutrition advisor. All participants were required to give informed consent. Participant recruitment was done until data saturation had been reached upon which recruitment of new participants was discontinued.

3.6. Sampling strategy

3.6.1. Inclusion criteria

To ensure that participants could provide consent to participate in the study, the inclusion criteria included participants 18 years and above. Community members, including primary caregivers and pregnant women were targeted as they are the main individuals who determine the mode of infant feeding and they are also the target group for donation (Coutsoudis, Petrites & Coutsoudis, 2011:2). The health care workers eligible for recruitment included doctors, dietitians, nursing staff and nutrition advisors working within maternity or paediatric sections within the chosen facilities. Nursing positions included enrolled nursing assistants,

enrolled nurses and professional nursing staff. Including these cadres of staff was important as they are involved in supporting infant feeding practices within the hospital and clinics. All participants were required to speak and understand either isiZulu or English. All participants were required to sign a consent form to be included in the study to ensure that the researcher protected the participants' rights (Klopper, 2008:71).

3.6.2. Exclusion criteria

Exclusion criteria excluded any mothers with postpartum psychosis which had been diagnosed by a medical officer. This information was screened by the researcher in the maternity record of mothers who had recently delivered infants. Healthcare workers who do not work in paediatric or maternity sections were excluded from the study. In addition, community members under the age of 18 years were excluded. Community members and healthcare workers who were not able to speak IsiZulu or English and any participants unwilling or unable to give consent for their participation were not included in the study.

3.7. Ethical considerations

The study was feasible to conduct in terms of limited available resources and was approved by the University of Cape Town (UCT) Human Research Ethics Committee, the University of KZN (UKZN) Biomedical Research Ethics Committee and the KZN DoH. This was done to ensure that the study adhered to the Declaration of Helsinki which includes several principles which guided the researcher in terms of the best interest of the participants involved (World Medical Association, 2001:373-374).

The study was designed in accordance with the principles of good clinical practice contained in the Belmont report (Ryan *et al*., 1979:1-9). Principles such as autonomy, beneficence, non-maleficence and justice were adhered to as well as explained in simple terms by use of the consent form. This includes "Respect for Persons" where all participants were required to give informed written consent to participate in the study after they were informed of the study aims and methodology. Consent forms were available in both English and IsiZulu. The researcher ensured that the participants were given all the necessary information regarding the study including the risks and benefits. All participants were given a choice of whether they

want to be a part of the study and were advised that they can withdraw participation at any time without any consequences.

Secondly, the principles beneficence and non-maleficence were adhered to as the researcher ensured that the study did not harm but provided more information pertaining to human milk banking which in turn could increase milk donation thus promote health for vulnerable infants. Confidentiality was ensured and information regarding the participants is not available to external stakeholders. All transcripts are kept confidential and electronic copies stored on a password protected computer. Participant codes are used to protect participants' identities. Codes with the letter "A" were assigned to healthcare workers and codes with the letter "B" were assigned to community members. If participants felt distressed during the interviews, they were informed that they were allowed to either have a break or to leave the interview without any penalties. However, none of the participants expressed any distress whilst being interviewed.

Thirdly, the principle of justice was considered where participation for the study was advertised and all those meeting the inclusion criteria were eligible to participate.

A risk-benefit review found that benefits to respondents were greater than the risk. There was no risk of harm to respondents anticipated in this research project as the questions were assessing knowledge, attitudes and perceptions.

All interviews were conducted in the most commonly spoken language, isiZulu and focus groups were conducted in English with a translator available if the healthcare workers needed to speak in isiZulu. Interviews and focus group discussions were conducted in a room with just the participants, interviewer and translator were present. The discussions could not be overheard by others and a note was left on the door to indicate that an interview is in progress.

The results of the study will be given to the KZN DoH and could help to change current practices and possibly provide information to implement a quality improvement plan within the institution or province.

3.8. Data collection

All participants were required to answer several questions pertaining to their characteristics and demographics. Method triangulation was used to verify data by using two methods of data collection which included interviews and focus groups. A range of interview questions were used to interpret topics such as knowledge, source of information, experience and opinion.

Community members participated in in-depth, semi-structured individual interviews which were conducted with only the researcher and translator present which ensured confidentiality and allowed participants to freely express themselves. The use of an interview schedule allowed the researcher to have prepared questions prior to the interview (DiCocco-Bloom & Crabtree, 2006:351). The interview schedules for community members was piloted with two respondents and one focus group with healthcare workers was conducted prior to use in the actual study to ensure that the questions were easily understood and that there were no ambiguous terms (Gill *et al*., 2008:292). The pilot study also showed the researcher the time taken to conduct an interview as well as if the respondents were able to give the interviewer the information that was required to meet the study objectives. The interview schedules were revised after the pilot study to ensure that the questions were easily understood. The interview schedules were translated into isiZulu which is the predominant language spoken within the area of the study sites. An experienced isiZulu speaking research assistant was recruited to assist with conducting interviews in IsiZulu.

Healthcare workers at the hospital and clinic were invited to participate in focus groups discussions. Strengths of using focus groups were that participants with the same attitude or culture (in this case it is healthcare workers who work within a similar environment) were able to discuss pertinent issues together and allowed participants to express their opinions (Ulin, Robinson & Tolley, 2005:44). The focus group discussions were conducted in English with a translator available to translate if participants wished to speak in isiZulu.

Audiotape recordings and detailed notes on body language of participants and social processes in the group were used to collect data (Skinner, 2014:352). In order to reduce potential bias, the researcher together with the research assistant facilitated the focus groups (Ulin, Robinson & Tolley, 2005:79).

Data was collected until data saturation was reached. Data saturation refers to the stage in the data collection process where no new themes emerge from new participants therefore no new information is required. Data saturation increases the trustworthiness of the research (Green & Thorogood, 2004:103).

3.9. Data analysis

3.9.1. Content Analysis

The style of the study data analysis was chosen to relate to the aim of the study. The aim of the study was to gain information on the knowledge, attitudes and perceptions of community members and healthcare workers towards human milk banking therefore interviews and focus group discussion were suitable methods of data collection. Qualitative content analysis was most appropriate to analyse the data collected and was done simultaneously with data collection (Green & Thorogood, 2004:176-177). Inductive content analysis was used which included three main phases namely, preparation, organisation and reporting of results. The preparation phase includes the researcher being immersed in the data and familiarising herself with the transcripts to ensure that they are well understood as well as selecting units of analysis. Here, the researcher reviewed the transcripts and field notes as well as listened to the audiotape recordings. Audiotape recordings in IsiZulu were translated into English transcripts for the researcher to analyse. Organisation refers to open coding, creating categories and abstraction. In the reporting phase, the results are described according to themes and sub-themes (Elo & Kyngäs, 2007:109-110).

3.9.2. Validity

There are various strategies to ensure validity of the data obtained. Firstly, triangulation was used to verify data by using two data collection methods including individual interviews and focus groups. External auditing included two experienced researchers reviewing the study methodology. In addition, a dietitian with a Masters' degree reviewed the data collected and determined if the findings were related to the data presented. Furthermore, data saturation also ensured that the data has high validity.

Chapter four

Results

4.1. Introduction

The following chapter will include a summary of the socio-demographic characteristics of the study participants and describe the themes and sub-themes that have been identified from the data analysis.

4.2. Socio- demographic characteristics of study participants

There were 44 participants interviewed in total. The socio- demographic characteristics are represented in Table 2 below. The participants reside in 3 different districts which are in the QNRH catchment area.

Table 2: Socio- demographic characteristics of the study participants

	Number of healthcare workers n=30 (%)	Number of caregivers n=14 (%)
1. Place of residence by District		
KCD	30 (100%)	11 (79%)
Umkhanyakude	0 (0%)	2 (14%)
Zululand	0 (0%)	1 (7%)
2. Sex		
Male	2 (7%)	0 (0%)
Female	28 (93%)	14 (100%)
3. Race		
Black	30 (100%)	14 (100%)
4. Age category		
18-34 years	11 (37%)	7 (50%)
35-45 years	18 (60%)	4 (29%)
46-60 years	1 (3%)	1 (7%)
> 60 years	0 (0%)	2 (14%)
5. Employment		
Healthcare worker	30 (100%)	0 (0%)
Sales assistant	0 (0%)	1 (7%)

Unemployed	0 (0%)	13 (93%)
6. Education		
Did not complete primary education	0 (0%)	1 (7%)
Primary	0 (0%)	5 (36%)
Secondary	0 (0%)	8 (57%)
Tertiary	30 (100%)	0 (0%)
7. Religion		
Christian	26 (87%)	12 (86%)
Nazareth (Shembe)	3 (10%)	2 (14%)
None	1 (3%)	0 (0%)
8. Marital status		
Married	7 (23%)	4 (29%)
Single	23 (77%)	10 (71%)
9. Location of interview		
QNRH	0 (0%)	7 (50%)
Empangeni clinic	0 (0%)	7 (50%)
10. Location of focus group discussion		
QNRH	18 (60%)	0 (0%)
Empangeni clinic	12 (40%)	0 (0%)

4.3. Identified themes

The following themes and sub-themes were identified during the data analysis and are presented in Table 4 below.

Table 3: Themes and sub-themes identified during data analysis

Title of theme	Sub-themes
1. Breastfeeding is an optimal feeding choice	- Benefits of breastfeeding - Experience with breastfeeding - Dangers of formula feeding
2. Infant feeding choice	- Challenges with breastfeeding - Influence on feeding choice - Physical appearance
3. Misperceptions of HIV	- Confusion regarding infant feeding in the context of HIV

	- Fear of HIV transmission - Mixed feeding
4. Knowledge of DHM	- Familiar concept - Fear of the unknown
5. Acceptance of DHM	- Cultural and religious beliefs - Testing and safety of DHM - Acceptability to donate breast milk - Acceptability to feed own infant DHM
6. Increase awareness and DHM collection	- Engage with the community - Compensation for donors

4.3.1. Breastfeeding is an optimal feeding choice

4.3.1.1. Benefits of breastfeeding

Both groups of study participants, healthcare workers and community members, felt that breastfeeding was the optimal feeding choice for infants. There were several benefits of breastfeeding that the participants expressed such as optimal growth and decreased risk of infections in infants.

Healthcare workers described many benefits of breastfeeding for infants. Participant 10A explained "*It's always warm. It's always at a good temperature, provides the baby with all the nutrients that the baby needs particularly for the first 6 months of life. You don't need to add anything to it. It enhances that bond between the mother and the baby as the mother breastfeeds… It also has anti-infective properties that helps the baby to not get sick easily during the period when the mother is breastfeeding*."

Healthcare workers also discussed breastfeeding being beneficial for mothers. Participant 18A said *"It also lowers the risk of the mother having breast cancer and osteoporosis"*.

4.3.1.2. Experience with breastfeeding

Community members frequently used the term "fresh" to describe breastfed infants which is the colloquial term for healthy. This is seen in the following quote where the participant

explained that her decision to breastfeed was influenced by seeing the optimal growth and health of her mother's breastfed infants.

"I could recall that her children were growing up very well, with smooth skin and they looked fresh. And her babies were not sickly babies [Laughs]." When probed to explain what the term "fresh" referred to, the participant explained *"Her children were fresh, nice skin, not skinny. Her babies did not get infections."* (Participant 4B)

This was reiterated by participant 6B who was currently a pensioner but had breastfed her 7 children many years ago "… *breast milk helps to protect babies from infections and sicknesses. They are not at risk of diarrhoea. They are often healthy babies. I can say breast milk helped somehow. Although I did not get formal school but as a mother I can say breast milk helped me a lot."*

4.3.1.3. Dangers of formula feeding

Most participants explained that there were several risks of feeding formula to infants. One nurse explained "*I think it can cause respiratory distress because of the chemicals in the formula feed*." (Participant 27A)

Another nurse, participant 4A also stated "*Formula can cause diarrhoea if it is not well prepared. Um, if the hands are not washed so it needs hygiene and if hygiene is not maintained then the baby can develop diarrhoea. Also, it causes constipation*."

In addition, one of the caregivers interviewed noted "*My grandmother, she used to tell me that in the olden days there were no formulas to be given to babies like it is in our days. Every baby was given breast milk and did not have so many sickness and infections as it is now. This concurs with what doctors said. Grandmother said there were no Vukasiyambamba babies, a weak baby… It is a baby that looks sick, with thin hair, easily catch on flu and colds"* (Participant 3B).

4.3.2. Infant feeding choice

4.3.2.1. Challenges with breastfeeding

The participants expressed that there are multiple factors which influence infant feeding choices. The healthcare workers stated that many mothers are unwilling to breastfeed due to perceived insufficient milk after delivery, especially mothers who have delivered via caesarean section. In addition, they explained that first time mothers struggle to breastfeed after delivery and require additional support to breastfeed. Teenage mothers usually have to go back to school and some mothers have to go back to work soon after the infant is born. The healthcare workers explained that these mothers usually choose to feed their infants formula as they feel breastfeeding would not be a feasible feeding option. According to Participant 7A "*Most mothers in our clinic are young children who still go to school so for them it's the best choice because they aren't at home for breastfeeding. Ya, and others are working so having the formula milk is convenient for them."*

During one focus group, the healthcare workers discussed storage of EBM and noted that it was not culturally acceptable to leave breast milk in the fridge making it impossible for working or school going mothers to exclusively breastfeed their infants.

4.3.2.2. Influence on feeding choice

Most caregivers added that their decision on how to feed their infants was influenced by nurses and doctors at the clinic or hospital that they attend. They expressed that most of the healthcare workers encouraged breastfeeding and that this is one of the reasons why they chose to do so. In addition, community members and healthcare workers noted that family members such as grandmothers are also influential with regards to the decision of infant feeding.

Both healthcare workers and community members noted that drinking hot drinks and use of Amahewu (liquid maize meal porridge) increases breast milk production which enables mothers to exclusively breastfeed their infants without needing formula milk. They discussed that all breastfeeding mothers should be drinking it as the use of these additional supplements have been used over a period of years within the Isizulu culture. "*Well, with our Zulu culture*

we know that if you are a breastfeeding mother you need lots of Mahewu and lots of porridge and lots of warms drinks. For me, my mother made a bucket of Mahewu, I drank it when I was breastfeeding and I had plenty of milk. When I took out my breast from the bra it just sprayed the way I had so much milk so I think it just helps with the milk. I think it's just for different cultures, not all the cultures do that." (Participant 6A)

4.3.2.3. Physical appearance

Healthcare workers also discussed that many younger women do not breastfeed as they do not want to change their physical appearance. This was discussed at length during the focus group discussions where healthcare workers noted that many women believe that breastfeeding causes "sagging breasts".

According to participant 5A "…*if you breastfeed your breasts are going to be like sagging and become ugly."*

In addition, participant 18 A also noted that "*..they also feel their breasts will start sagging*."

4.3.3. Misperceptions of HIV

4.3.3.1. Confusion regarding infant feeding in the context of HIV

There is confusion amongst healthcare workers regarding infant feeding in the context of HIV. Most healthcare workers were uncertain when breastfeeding is contra-indicated in the context of HIV. Some participants stated that a high maternal viral load was a contra-indication to breastfeed. However, participants gave different definitions of a high maternal viral load whilst others were not sure of the definition of a high maternal viral load. Different suggestions included a viral load that is undetectable, less than 20 copies or less than 1000 copies. In addition, nursing staff at QNRH emphasised that preterm infants whose mothers' viral loads are not suppressed should be given DHM during the admission and then switch to infant formula on discharge.

Participant 2A commented "*There are instances where some HIV positive women can't breastfeed. In terms of the viral load of the mum. If it is very high, it is advisable that the mum*

doesn't breastfeed so she should opt for formula feeding instead of breastfeeding." When the nurse was asked if breastfeeding should be recommended if the mother was on ARVs, she stated "*if the viral load is high, it is not advisable to breastfeed because the mother can say I am taking my meds but she's not taking them properly so that's the main reason that the viral load is not going down so it could be that she's saying something else but she's doing something else or the regime that she's currently on is not suitable for her*."

This was highlighted by another nurse "*They start ANC [antenatal care] late and then by the time they deliver their viral load is still very high so we wouldn't allow them to breastfeed*." (Participant 18A)

One community member noted that maternal viral load needed to be taken into account when choosing the mode of infant feeding. "*I know that it has something to do with viral load, then that detects whether mother can breast feed of not*". (Participant 14B)

In addition, Participant 16B (a community member) stated that "*Mothers' CD4 count gets tested to check whether the levels allow her to breast feed or not."*

4.3.3.2. Fear of HIV transmission

This sub-theme of "Confusion regarding infant feeding in the context of HIV" is closely related to "Fear of transmission". Most respondents expressed that HIV transmission must be avoided and that the risks of HIV transmission to an infant outweigh the benefits of breastfeeding and dangers of formula feeding when choosing the mode of infant feeding. Despite the dangers of formula feeding which the participants discussed, there is a misperception regarding the safety of breastfeeding in the context of HIV.

Several community members were concerned about this. When asked to discuss her perception of HIV positive mothers breastfeeding, one mother remarked "*…I feel bad when I think of the risks involved. I think what if the baby gets infected through breast milk. I know that HIV mothers are taught to breast feed for six month then after to give formula milk. I do not know how safe that is… I think there are risks involved when mothers breastfeed when they are HIV positive*" (Participant 15B).

Another mother explained "*The doctor told me that there is no problem I can breast feed this baby. This baby too will be fresh because I will not infect him with HIV. However, I do not have assurance about that I will know when the time comes for testing*" (Participant 16B).

Healthcare workers explained that HIV positive mothers are afraid of infecting their infants with HIV. "*Some of them they think when they are breastfeeding especially when they are HIV positive they think that they will infect the children*" (Participant 24A).

4.3.3.3.Mixed feeding

The healthcare workers interviewed explained that HIV exposed infants are at risk of mixed feeding if mothers do not disclose their HIV status to the rest of the family. They mentioned that the elders in the family usually introduce solid foods to infants early (before 6 months of age). Therefore mothers choose to formula feed to avoid mixed feeding of breast milk and formula milk to ensure that there is no risk of transmission of HIV.

Participant 10A " *…it is difficult to say you're going to breastfeed exclusively with an adult on the other hand is pushing you to give your baby something else early so then it's much better for mothers to choose or opt to just give formula because they are afraid because they are taught at the clinic that mixed feeding may increase the risk of transmission so it's far better for them to opt for formula feeding over breastfeeding because if for instance they are sent to town the baby will be left with gogo [grandmother]and gogo may try her luck by feeding the baby porridge while the mother is away so that directly affects HIV exposed mothers with their choice to breastfeed exclusively."*

However, a caregiver explained that mothers are aware of the benefits of breastfeeding and would sometimes choose to mixed feed rather than exclusively formula feed to ensure that they gave the infant the benefits of breast milk *"…breast milk is good and it is helpful to a baby especially to mothers like us that are unemployed. Even if you are employed some mothers feed breast milk when they are with the baby and feed formula milk only if they are at work. Although nurses taught us not to mix feed but because mothers want to give their babies the best that they can*". (Participant 6B)

4.3.4. Knowledge of DHM

4.3.4.1. Familiar concept

Most healthcare workers were aware of the concept of breast milk donation. However, knowledge was greater amongst QNRH staff members, specifically those who worked in the neonatal unit. These healthcare workers could explain the process of human milk banking. The healthcare workers who were familiar with DHM stated that they would donate their breast milk as well as give consent for their own infants as they know that it is safe because all donors are screened and DHM is pasteurised as well as tested thereafter to ensure quality control. Several participants in both groups explained that they had had experience with DHM and were generally more convinced of its efficacy.

4.3.4.2. Fear of the unknown

Most community members attending Empangeni clinic had not heard of human milk banking. In addition, there were two mothers who were interviewed who had just given birth and were currently admitted in the postnatal ward of the hospital. They had not been informed about human milk banking and reported that they would not feel comfortable consenting for their infants to receive DHM.

Participant 15B was breastfeeding her infant but despite being assured that DHM was tested to ensure that it is safe the participant still had the same response "*...they can say they have tested milk and have ensured that it is safe for baby's feeding but the baby may have some reactions to that donated milk*." This participant also felt that donating milk was not acceptable as she would not have enough milk for her own infant and felt that if she had to donate milk she would have to feed her infant formula milk.

Participant 16B also chose to breastfeed her infant and reported that she did not find DHM acceptable as she had not heard of it before. "*No I do not think so, I can just imagine my baby feeding on someone else's breast milk mmh I can't*."

4.3.5. Acceptance of DHM

4.3.5.1. Cultural and religious beliefs

Healthcare workers noted that wet nursing was a common practice by community members who had previously breastfed. One healthcare worker explained that she had wet nursed her sister's infant and vice versa. She also explained that she was wet nursed by her grandmother and it was acceptable a few years ago however, that has changed due to the high rate of HIV within the community.

In addition, the participants expressed that certain cultural or religious beliefs could impact the acceptance of DHM. For example, Jehovah's Witness do not accept blood products therefore they may not find it acceptable to accept DHM. A community member commented "*Some people would rather die other than to receive donated blood or organs because of their religion. It [religion] does have influence*". (Participant 9B)

Two male healthcare workers were part of the focus group discussions at Empangeni clinic. They did not receive formal training on human milk banking but were aware of the programme at QNRH. They reported that they would not find it culturally acceptable to consent for their infants to receive DHM.

"*It's also about our cultural beliefs. We, the African natives we do not necessarily believe in milk and even blood being donated… They don't subscribe to such things donating my own milk to a baby I don't know*." (Participant 10A)

4.3.5.2. Testing and safety of DHM

Acceptance of DHM appears to be related to perceptions of the safety of this feeding option as testing is done before it is given to the recipient infant. Participant 9B, a community member noted "*Yes I would allow it for my baby to get donated breast milk because I think there are some tests that it goes through. Life has changed, there are diseases that one needs to be mindful of. As I have mentioned that it is possible for HIV mothers to breast feed their own children. Because I will be getting donated milk from hospital I will know that it is safe enough to give to my baby."*

Participant 11B reiterated "*I would permit for my baby to get donated breast milk because just like in my case I wanted to breast feed but because of situation I could not because I developed sores... I would allow it, for my baby to receive donated breast milk as long as I know that the donated milk has been tested and it is safe*".

Most healthcare workers were aware that potential donors are screened for HIV and therefore found it to be acceptable. The issue of HIV was found to be the most significant factor to safety of DHM.

4.3.5.3.Acceptability to donate breast milk

Most of the female healthcare workers explained that they would donate their breast milk as they would feel it is their responsibility to help infants. One participant was a previous donor at QNRH and said there are benefits for the donors who work at the hospital as she was given time off during the day and a room was made available for her to express.

Some community members also noted that they would want to assist vulnerable infants if they do not have access to OMM. "*I feel that it is the right thing because it helps those mothers that cannot produce breast milk*." (Participant 12B)

However, many community members were not at ease with donation and explained that they would need time to think about it before they donated their breast milk. "*Imagine giving away my own milk. I do not support this milk donation thing. I am not happy about it*." (Participant 16A)

4.3.5.4.Acceptability to feed own infant DHM

Acceptance of DHM was expressed by many participants who have and have not been exposed to human milk banking. Most healthcare workers noted that if the infant's birth weight is normal and if the infant were not sick, they would not consent to DHM feeding. However, if the infant were preterm or low birth weight, they would consent to DHM as they felt it could be lifesaving instead of giving formula milk. One healthcare worker noted that consent for acceptance of DHM should be noted during the antenatal period in the maternity

records of the mother to ensure that her consent was given in cases where a mother is sick or if she demised during or after delivery.

The majority of community members indicated that they would consent for their infants to receive DHM in cases where OMM was not available. However, a few community members did not feel comfortable with their infants receiving DHM. "*Yes the baby needs it [DHM] but I will not allow it. I would prefer that they get milk from the cows, boil it then feed the baby. Milk the cow, boil milk, cool it down and then feed the baby or else make Incumbe. Boil dried corn, stone crush it and feed the baby*". (Participant 10B)

4.3.6. Increase awareness and DHM collection

4.3.6.1. Engage with the community

In general, the participants noted that more awareness is required to increase the acceptability of human milk banking. Healthcare workers advised that campaigning for human milk banking should also be conducted outside healthcare facilities, within the community, targeting men and the elderly as they are likely to influence the decisions of mothers. The participants added that human milk banking needs to be advertised in the media such as the radio. Healthcare workers explained that they required more information on human milk banking in order to promote the concept in the workplace and communities.

4.3.6.2. Compensation for donors

Healthcare workers suggested that the DoH should provide compensation to increase milk donation. They suggested that small tokens or financial remuneration should be given to potential donors to increase milk donation. They noted that community members will feel as if they are giving something of value and would need to get something in return. "*Our people also believe in getting a stipend so maybe per 100ml we will get 10 bucks"* (Participant 10A).

Participant 27A remarked "*Those mothers here in nursery donating donor milk but I saw that when they were given Amahewu, there was a time they were given Amahewu, they were donating even more. It stopped and then they didn't want to give anymore so that we have to give something*."

Chapter five
Discussion

5.1. Introduction

In chapter four, results of the evaluation of the knowledge, perceptions and attitudes regarding the donation and use of DHM amongst community members and health care workers in Empangeni, KZN were presented. These results varied according to participants' knowledge, exposure, culture and experience related to the use of DHM. This chapter will discuss these results.

5.2. Breastfeeding is an optimal feeding choice

In general, participants, both health workers and community members, supported breastfeeding as an optimal feeding choice as they had observed improved health and less illness in breastfed infants. Similarly, Mnyani *et al*. (2017:4) also found that pregnant and postpartum women with prior breastfeeding experience and more knowledge on infant feeding in the context of HIV were more likely to exclusively breastfeed.

However, despite the knowledge of the benefits of breastfeeding and the revised national PMTCT guidelines which clearly indicate that HIV positive women should breastfeed, distrust of the safety of breastfeeding in the context of HIV is resulting in some healthcare workers still recommending formula feeding for these women. Furthermore, though community members expressed concern that formula fed infants did not appear to be as healthy as those who were breastfed, many caregivers still choose to formula feed their infants due to the fear of HIV transmission.

In addition, there is a high rate of under-5 year Severe Acute Malnutrition (SAM) within this area. SAM in children under the age of 12 months is often due to poor infant feeding practices including inadequate or no breastfeeding, incorrect preparation of infant formula and very early introduction of solids (Hendricks, Goeiman & Hawkridge, 2013:44). KCD is also one of the worst performing districts in South Africa with a SAM case fatality rate of 9.6% (Massyn *et al*., 2015:35). Therefore, more advocacy and engagement amongst the community and

healthcare workers is required regarding infant feeding (specifically in the context of HIV) to improve breastfeeding rates and subsequently decrease the rate of SAM in infants.

5.3. Infant feeding choice

Healthcare workers at the clinic and hospital were reported to be influential around infant feeding choice and are ideally suited to support mothers who face various challenges after delivery, particularly first time mothers, teenagers and those with multiple births. Healthcare institutions are important places for breastfeeding advocacy amongst pregnant women and mothers. There is a high teenage pregnancy rate within the area and healthcare workers noted that it is often younger mothers who do not want to breastfeed due to fear of changes of their physical appearance. Teenage mothers usually go back to school and leave infants with grandmothers who may struggle to prepare formula feeds correctly. Although there is a high breastfeeding initiation rate, breastfeeding is not sustained. Horwood *et al*. (2018:6-7) conducted a study in KZN which showed that mothers who had to go back to work or school were less likely to breastfeed their infants at 14 weeks. Breastfeeding policies within the workplace should be implemented to assist working mothers as per the BCEA which allows for two thirty minute breaks for breastfeeding mothers (BCEA, No. R. 1441, 1998). Additionally, the government needs to ensure that organisations adhere to these policies. Furthermore, early expression soon after delivery and safe storage of EBM at room temperature for up 8 hours should be advocated by healthcare workers for mothers going back to school or work after delivery (WHO, 2009b:32). During the focus group discussions, it was noted that it is sometimes unacceptable for EBM to be stored in a fridge with other food items. Therefore, more community engagement is required to increase the knowledge and acceptability of the refrigeration of EBM amongst family members if mothers are away from their infants for long periods of time.

5.4. Misperceptions regarding HIV

The confusion regarding infant feeding in the context of HIV amongst both healthcare workers and community members is alarming. All healthcare workers expressed that breastfeeding is contra-indicated in the presence of a high maternal viral load. Nursing staff advocated for use of DHM in preterm infants and formula in the management of term infants as they did not feel it was safe for a mother with a high viral load to breastfeed. They noted

that this is their understanding of the National PMTCT guidelines. According to Kuhn & Kroon (2015:2), DHM can be used as a short term method of feeding however, HIV positive mothers could also heat treat their own EBM so that breast milk feeding can be sustained after discharge. During this period mothers should be supported with ARV adherence to ensure viral suppression as well as infant prophylaxis which together has a protective effect against HIV transmission. In addition, the guidelines note that only mothers with second or third line ARV treatment failure should not breastfed.

The fear of HIV transmission is widespread amongst healthcare workers and community members. This is despite the change of guidelines for advocacy of breastfeeding amongst HIV positive women. It has been shown that healthcare workers often overestimate the risk of HIV transmission during breastfeeding when counselling mothers (Doherty *et al*., 2012:2). Moreover, research conducted in Johannesburg showed that healthcare workers and women perceived that the risk of HIV transmission outweighed the benefits of breastfeeding. It was found that the poor counselling received was influential on infant feeding decisions. It was also noted that the frequently changing PMTCT guidelines may have caused confusion for healthcare workers which in turn negatively affects counselling of mothers. This emphasises that optimal training based on current guidelines should be provided for healthcare workers to enable them to give mothers accurate counselling on infant feeding as well as to support their infant feeding decision (West *et al*., 2019:5-6).

Early mixed feeding is a common practice within this community and in South Africa in general. According to Mnyani *et al*. (2017:7), exclusive breastfeeding is generally linked to a positive HIV status therefore women may not exclusive breastfeed and choose to mixed feed to avoid the stigma of HIV. This is despite mixed feeding without appropriate ARV cover increasing the risk of HIV transmission. In order to promote and support exclusive breastfeeding, male partners should be involved. Moreover, community-based peer groups may also provide mothers with the support they require to exclusively breastfeed (West *et al*., 2019:6).

5.5. Knowledge of DHM

Human milk banking was a familiar concept to most healthcare workers as much training and advocacy is done at QNRH. Coutsoudis, Petrites & Coutsoudis (2011:6) found that those who

are familiar with the practice often find it more acceptable as they are aware of the value of the use of DHM. This was evident in healthcare workers who had been trained on human milk banking and had also seen the benefits in patients who received DHM. Similarly, within the community, Goodfellow *et al*. (2016:85) reported that training on community-based human milk banks had improved mothers' perceptions of it.

However, safety issues were voiced as a concern amongst many community members suggesting a significant distrust regarding DHM. This could be as a result of a lack of experience of the concept of milk banking and the procedures involved in screening, processing and testing the DHM. Healthcare workers need to ensure that caregivers are given all the necessary information regarding DHM. Thereafter, caregivers may require some time to discuss the concept with family members and to know more about the processing of the milk before it becomes acceptable.

Furthermore, one mother mentioned breast milk donation may lead to poor supply of OMM. Mondkar *et al*. (2018:4) also reported that mothers may be hesitant to donate due to not having enough breast milk for their own infants. Firstly, mothers should receive comprehensive counselling that DHM is collected by the human milk bank staff once a mother has fed her infant and has a sufficient milk supply. In addition, mothers should be counselled on the physiology of breast milk production which includes an increased milk supply when breast milk is removed from the breast (when a mother breastfeeds or expresses breast milk frequently) (Abhulimhen-Iyoha *et al*., 2015:225).

5.6. Acceptance of DHM

Wet nursing was discussed by several participants as it was previously acceptable and a common practice within the community. However, it was noted that it is no longer practised due to the high rate of HIV. Similar results were found in the North West Province where many participants were aware of the practice however the fear of diseases or transmission of HIV has prevented community members from wet nursing. In this study, some participants indicated that if they knew the woman and her HIV status, they would be more willing to allow their infants to be wet nursed (Lubbe *et al*., 2019:5).

Jehovah's Witnesses were noted to possibly not accept the use and donation of human milk. This was the only religion that the participants discussed that could potentially not be accepting of human milk banking. It is important to note that none of the participants included in this study were Jehovah's Witnesses and had discussed that breast milk donation could be compared to blood donation which is a prohibited practice within the religious belief. There is however, limited research specifically looking at the use of DHM within the Jehovah's Witness community. According to Kadioglu, Avcialpar & Sahin (2018:1073), within this religion, blood transfusions are forbidden but there are no particular rules regarding the use of DHM. Further studies are required in this area.

The small sample of male healthcare workers explained that donating and receiving DHM was culturally unacceptable. Gender may play a role in acceptance of human milk banking as discussed by Lam, Keckés & Abdel-Latif (2012:836), as some research suggests that most females healthcare workers might be more knowledgeable regarding breastfeeding and lactation topics. However, most research conducted on attitudes and perceptions of human milk banking includes mostly females with a limited number of males consequently there is little known about males attitudes and perceptions of DHM. Conversely, Kimani-Murage *et al*. (2019:3-7) evaluated perceptions of human milk banking in Kenya. A small sample of fathers were included in focus group discussions with several fathers noting that they would be supportive of human milk banking if the DHM was safe to use and if it were of benefit to vulnerable infants. However, perceptions of males in Kenya may differ to those in South Africa. The male nursing staff in the current review noted that human milk banking was not culturally acceptable thus more data is required on the perceptions and attitudes of black males living in KZN.

As discussed in the literature review, the high prevalence rate of HIV in KZN and fear of HIV transmission may impact the acceptability of donating milk or mothers consenting for their infants receiving DHM (Coutsoudis, Petrites & Coutsoudis, 2011:2). The healthcare workers who were accepting of human milk banking were convinced that the screening, pasteurising and testing that is conducted ensured that the DHM is safe for use in infants. In addition, when the community members were aware that DHM was collected from HIV negative women, it was considered safe. Safety of DHM and the risk of HIV transmission were also the main factors contributing to acceptance of DHM according to Lubbe *et al*. (2019:6). Therefore, the donor inclusion criteria of a negative HIV status can assure recipients'

caregivers and families that the donor has been screened for HIV before donating breast milk. This should be discussed with the legal guardian before recipient consent is requested (KZN DoH, 2016:9-12). Similarly, Kimani-Murage *et al*. (2019:8-9) also found that participants felt the screening of donors, pasteurisation and testing of DHM for contamination ensured that DHM was safe thus should be highlighted to community members when discussing human milk banking.

Many healthcare workers explained that they would donate breast milk as they have been exposed to the benefits of DHM as well as wanting to help vulnerable infants who do not have access to their OMM. Some community members were also interested in donating milk. Thomaz *et al*. (2008:75) also found that donors felt a social responsibility to donate breast milk and a sense of gratification by helping infants. This aspect should be considered when campaigning for human milk banking and recruiting donors to increase the number of donors.

However, during an interview, one grandmother remarked that she feared the availability of DHM may cause younger mothers to not breastfeed their own infants. Contrarily, research conducted in a NICU in the USA showed that the presence of a human milk bank was associated with improved OMM feeding (Parker *et al*., 2016:227). Furthermore, a systematic review of 10 research studies on use of DHM on maternal breastfeeding rates showed that there was a significant increase on breastfeeding at time of discharge in the majority of the studies but there were was one study which indicated OMM feeding decreased after the introduction of DHM. The different findings may be attributed to the various indications for DHM within the study settings. No effect was found on exclusive breastfeeding on discharge (Williams *et al*., 2016:218). Stakeholders must be aware that the use of DHM is usually a short term intervention and the aim is to provide breast milk when OMM is not available (KZN DoH, 2016:5). If mothers are well enough, ideally they should start expressing breast milk as soon as possible after delivery with the aim of exclusive breastfeeding on discharge. Healthcare workers within the neonatal units have the responsibility to assist mothers with frequent (1-2 hourly) hand expression and provide continuous support and counselling on breastfeeding during admission to ensure that mothers establish a good breast milk supply which will enable them to exclusively breastfeed at the time of discharge (WHO, 2009a:6).

Some healthcare workers mentioned that though they would consent for their infants to receive DHM, they would only agree if their infants were preterm. Lam, Kecskés & Abdel-

Latif (2012:835) also found that nurses and doctors found infant formula preferable to DHM when feeding term infants. The reasons were not discussed in the literature but could possibly be due to limited research on the use of DHM in term infants. In the current research setting, DHM is primarily indicated in the management of only VLBW infants due to a limited supply however there are benefits of breast milk feeding for all infants which infant formula does not provide. A case series of term infants who were either HIV exposed or positive who were fed DHM suggests that they had improved growth with a possible reduced risk of opportunistic infections which is of considerable benefit to these vulnerable infants (Reimers *et al*., 2018:6). This highlights the need for increasing DHM collection for vulnerable, term infants. In addition, further training is required for healthcare workers to advocate for this.

A few community members reported that they would not consent for use of DHM. Participants were more willing to donate breast milk rather than giving it to their own infants. As discussed by Abhulimhen-Iyoha *et al*. (2015:225), this is likely related to fear of infants developing illnesses or contracting diseases from the DHM. In one instance, a grandmother noted that she would boil fresh cow's milk for the infant rather than consenting to DHM. More awareness within the community structures is required to improve the acceptability of DHM. In addition, the dangers of formula feeding of vulnerable groups should be highlighted as some participants explained that they would prefer the use of infant formula instead of DHM.

5.7. Increase awareness and DHM collection

The participants mentioned that more community awareness and engagement around human milk banking was needed to increase the acceptability of DHM. There was a willingness to promote breastfeeding and human milk banking by both healthcare workers and community members. Due to community members' strong influence on infant feeding choice, the extended family, elders and men in the community should be included in the programmes to raise awareness.

A study conducted in India explored the effect of family members on mothers with regards to use of DHM. The influencers included the neonates' fathers and grandmothers. It was found that fathers were initially concerned about their infants receiving DHM but after receiving more information on the safety of DHM, found the use of it more acceptable. Grandmothers

also felt uncomfortable about DHM use but did not receive any information regarding human milk banking during the study and reported that they had not seen any educational material on human milk banking in the hospitals. Therefore, family members need to be counselled regarding DHM use within the unit in order to improve their perceptions and ensure that they are supportive of it. Educational material should be made available both in the hospital setting and community to increase awareness (Mondkar *et al*., 2018:6-7). Campaigns within the community should also be aimed at all stakeholders including grandparents and partners (Goodfellow *et al*., 2016:85).

Furthermore, infant feeding choices are influenced by health education received during the antenatal period (Lubbe *et al*., 2019:7). Therefore, promotion of breastfeeding in general and human milk banking should be started during antenatal care for pregnant women to ensure that the concept becomes familiar and they can contemplate being potential donors as well as consider consent for their infants to receive DHM should they not be able to provide OMM (Mondkar *et al*., 2018:6). In order to adequately promote human milk banking during the antenatal period, healthcare workers need appropriate and comprehensive training in both breastfeeding (especially in the context of HIV) and human milk banking to provide factual, evidence based information to answer questions which may arise from potential donors.

Financial remuneration or gifts to donors was suggested by healthcare workers but not discussed by community members as an incentive to increase the number of donor mothers. The research conducted by Iloh *et al*. (2018:7-11) in Nigeria found that a relatively small number of mothers required compensation for donating breast milk. However, the majority of mothers in the study who indicated that they did not require financial incentives were more likely to donate their breast milk. Therefore, financial remuneration may not have an influence in increasing the number of donor mothers.

In addition, in South Africa breast milk is classified as a tissue and is governed by the Human Tissue Act which forbids monetary payment for DHM (Reimers, 2017:54). The Human Milk Banking Association of North America (HMBANA) approves of non-profit human milk banking to safeguard against donors supplying banks with diluted milk as well as to ensure that DHM is allocated to infants in an ethical and safe manner (Iloh *et al*., 2018:11). Buying breast milk online is a common practice in the USA however, donors are not screened via a human milk bank and the DHM is not pasteurised or tested. Keim *et al*. (2015:e1159-1160)

found adulteration of samples of DHM purchased on the internet with cow's milk or infant formula. It is likely that the sellers of the DHM add cow's milk or infant formula to increase the volume of milk that they are selling to make a larger profit. The recipients of the DHM purchased online are subsequently at risk of contracting infections or diseases.

Both healthcare workers and mothers mentioned that drinking Amahewu assists with improving breast milk supply. This perception has previously been noted in KZN (Jama *et al*., 2017:11). At one stage, QNRH gave additional Amahewu to donor mothers to increase breast milk production, however within this setting this may have a negative effect on breastfeeding mothers who may have a perception that supplementation is required to produce breast milk. Further research is required to confirm the efficacy of Amahewu supplementation on breast milk supply (Nduna, Marais & van Wyk, 2015:74). In addition, supplementation of donor mothers with Amahewu is no longer practised at the hospital and there are still fluctuations in DHM collected (Nyawo, personal communication 2019, November 29).

Some nursing staff suggested that small gifts be given to mothers to show gratitude for the valuable resource that they have given. At QNRH, this is done during Breastfeeding week where human milk banking is highlighted and donor mothers are given gifts as a token of appreciation (Mshengu, 2019).

5.8. Strengths and limitations

The study design and methodology was ideally suited to the study aim and objectives and is a strength of the study. The qualitative design allowed for participants to discuss their knowledge, attitudes and perceptions in more detail and to share their own experiences. In addition, two groups of participants were included to ensure that healthcare workers and community members could engage in discussions.

Limitations of the study include a lack of data collection from rural areas, a small sample size of men and mostly nursing staff were included in the healthcare workers sample. Clinicians, who are also important stakeholders and influencers on human milk banking were not part of this study. In addition, community healthcare workers who play a pivotal role within their communities were not included in the sample.

Chapter six
Conclusion and Recommendations

6.1. Conclusion

Chapter six summarises the findings and incorporates key recommendations for future studies and implementation of human milk banking.

This research explored knowledge, perceptions and attitude of community members and healthcare workers regarding the donation of breast milk and use of DHM in Empangeni, KZN. Although most participants, including healthcare workers appeared to be aware of the beneficial effects of breastfeeding, this knowledge does not translate into a change in practice, with many not following or recommending exclusive breastfeeding for six months. The apprehension regarding the safety of breastfeeding in the context of HIV seems to be a major concern and this appears to be related to the safety of DHM. In general, most healthcare workers were knowledgeable about human milk banking but despite the local human milk bank being launched over 4 years ago, there are still barriers to donating and receiving DHM which include fear of transmission of HIV and the concern that DHM is not safe. In addition, cultural beliefs were found to impact the acceptability of DHM.

6.2. Recommendations

Addressing the misinformation that exists amongst healthcare workers is of utmost importance to ensure they are giving updated, evidence-based information (in accordance with national guidelines and policies) and counselling to patients and their families. This, together with the lack of awareness, understanding and acceptance of DHM within the community requires an important public health initiative to educate the community on the benefits of breast milk feeding which includes OMM and DHM. Community engagement should be done through existing community structures, religious institutions and working with local community leaders. Community engagement should include all stakeholders such as mothers' partners and the elders. This can be done by community healthcare workers who conduct home visits during the antenatal and postnatal period. They should be trained on human milk banking and therefore can discuss DHM at a community level and can therefore

recruit and collect DHM. This should be an important strategy for the KZN DoH as it is believed to improve the acceptability of DHM.

In addition, theory- based interventions such as behaviour change methodology which includes targeting mothers' specific challenges with regards to breastfeeding and giving them practical support to breastfeed may improve behaviour change thus increase breastfeeding rates.

Moreover, the establishment of peer support groups could be used within the community where breastfeeding mothers can support each other. Support group members can also include donor mothers and mothers of recipients of DHM who can share their experiences regarding DHM. Local community healthcare workers who have been trained on breastfeeding and human milk banking could facilitate these groups. This may lead to improved acceptability of human milk banking which can in turn improve breastfeeding rates within the area.

In addition, the education and support of parents within the NICU setting about the benefits of using DHM as well as the processing of DHM may make them feel more involved in the care of their infant and more comfortable with DHM use. Monetary compensation should not be advocated for by staff members although donor mothers can be given small tokens of appreciation. However, this initiative should not be used to recruit donors. During campaigning, the DoH should appeal to communities to be supportive of the practice as it can be life saving measure for vulnerable infants. Human milk banking should also continue to be highlighted during Breastfeeding Week. Furthermore, MomConnect is an initiative of the National DoH whereby pregnant women and mothers can register to receive weekly text messages pertaining to maternal and child health. This can be an avenue used for sharing more information regarding human milk banking.

There was a small sample size of males so further research in this area is recommended to include more males. Additional research is also required regarding human milk banking and religious beliefs, particularly Jehovah's Witness. Furthermore, the study sites were located within an urban area. More date needs to be collected within more rural areas which also includes community healthcare workers who play a pivotal role in infant feeding support within the communities. There were no clinicians who participated in the study therefore further research is required in KZN involving medical doctors.

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Appendix 1

Socio-demographic questions

1. Place of residence _____
2. Participant code _____
3. Gender _____
4. Race _____
5. Age _____
6. Occupation _____
7. Highest level of education _____
8. Religion _____
9. Marital status _____

Appendix 2

English interview schedule for community members

Assessing Knowledge

1. Which method of infant feeding is most beneficial to babies and why?
2. Why is breastmilk important for babies born who are early?
3. What would happen if these babies don't get breastmilk?
4. How do you feel about mothers with HIV breastfeeding their babies?

Assessing Attitude

1. How have you fed you own baby?
2. If baby was ever breastfed, how long did you breastfeed for?
3. What were the reasons for you to decide to feed your baby that way?
4. Who guided you to make this decision?
5. Have you heard about breastmilk donation? If so, from where?
6. How do you feel about breastmilk donation and would you donate breastmilk?
7. How do you think we can get more mothers to donate breast milk?
8. If you were not able to provide enough of your own breast milk for your baby, how would you feel about providing your baby with donated breast milk?

Appendix 3

Zulu interview schedule for community members

Le mibuzo elandelwayo izobe ibhekiswe kubanakekeli emakhaya

Ukuhlola ulwazi

1. Iyona yiphi indlela engcono yokudla ebantwaneni abancane, futhi kungani usho lokho?
2. Ubona libaluleke ngani ubisi lwebele ebantwaneni abazalwe kungakashayi isikhathi sabo?
3. Kuzokwenzakala ini uma laba bantwana bengalutholi ubisi lwebele?
4. Uzizwa kanjani ngomama abanesandulela ngculazi ukuthi bancelise ubisi lwebele?

Ukuhlola indlela abuka ngayo izinto

1. Abantwana bakho bona ubancelisa ini?
2. Kulabo owabancelisa, uncelisa isikhathi esingakanani?
3. Ngabe yiziphi izizathu ezenza wena ukuthi uncelise ngalolo hlobo?
4. Ubani owakusiza ukuthi uthathe leso sinqumo?
5. Usuke wezwa mayelana nokunikelwa kobisi lwebele, uma kunjalo ngawe wezwa kuphi?
6. Uzizwa kanjani mayelana nokunikelwa kobisi, futhi ungathanda yini ukunikela ngobisi lwebele?
7. Ucabanga ukuthi kungenziwani ukuthola omama abaningi ukuthi banikele ngobisi
8. Uma bekwenzeka nje ukuthi ungakhoni ukuba nobisi olwanele ukuncelisa ingane yakho, ubungathini nje ngobisi lwebele olunikeliwe ukuncelisa ingane yakho?

Appendix 4

English interview schedule for healthcare workers

1. What are the benefits of breastfeeding?
2. What are the risks of formula feeding preterm babies?
3. Why do you think mothers choose formula instead of breastfeeding?
4. Do you support mothers to breastfeed? If so, how do you support them?
5. What are the reasons that mothers struggle with milk production after delivery?
6. How does HIV affect infant feeding choices?
7. What is the importance of donor milk in the management of preterm babies?
8. What are the challenges with collecting donor milk?
9. Do you feel donor milk is safe to give to babies?
10. Would you give your own baby donor milk? If not, why not?
11. What are the challenges with mothers consenting for their babies to receive donor milk?
12. How do you feel about promoting donor milk?
13. Would you be willing to be a donor mother? If not, why? If yes, why?
14. What do you think can be done to improve breastfeeding rates within the area?
15. How do you feel about breastfeeding mothers drinking Amahewu?
16. What do you think can be done to improve donor milk collection and acceptability of donor milk?

Appendix 5

Zulu interview schedule for healthcare workers

1. Bunabuphi ubuhle ukuncelisa ubisi lwebele?

2. Bunabuphi ubungozi ukupha ingane ezalwe kungakabi isikhathi ubisi lwethini?

3. Ngokwakho, kungani abazali beqoka ukuncelisaubisi lethini kunokuncelisa ubisi lwebele?

4. Ingabe uyabeseka yini abazali ukuthi bancelise ibele, uma kunjalo ubeseka kanjani?

5. Yiziphi izizathu ezenza omama basokole ukuncelisa ubisi lwebele uma beqeda ukubeletha?

6. Ingabe isifo sengculaza sona siphazamisa kanjani ekukhetheni indlela ofisa ukupha ngayo umntwana?

7. Lubaluleke ngani ubisi lwebele ezinganeni ezizalwe kungakabi yisikhathi?

8. Yiziphi izingqinamba mayelana nokukoleka ubisi olunikeliwe?

9. Ngokwakho, ngabe ubisi lwebele olunikeliwe luphephile yini ukuba lunikwe abantwana?

10. Ungamunika yini owakho umntwana ubisi lwebele olunikeliwe, uma ungeke, ngabe kungani?

11. Yiziphi izingqinamba abazali ababhekana nazo ukunika imvume ukuthi abantwana bathole ubisi lwebele olunikeliwe?

12. Uzizwa kanjani mayelana nokuphakamisa ukunikelwa kobisi lwebele?

13. Ungavuma yini ukuba unikele ngobisi lwebele, uma ungeke, ngabe kungani? Uma uvuma yisiphi isizathu?

14. Yini obona ukuthi ingenziwa ukusiza ukukhuphula izinga lokunceliswa kobisi lwebele kule ndawo?

15.Uzizwa kanjani ngomama abancelisa ibele uma bephuza amahewu?

16.Yini obona ukuthi ingenziwa ukukhuphula izinga labanikelayo ngobisi lwebele, Kanye nokwamukeleka kobisi lwebele olunikeliwe?

Appendix 6

Participant Information Sheet and Consent Form (English)

This Informed Consent Form is for community members residing within King Cetshwayo district as well as healthcare workers employed at Queen Nandi Regional Hospital (QNRH) and Empangeni clinic who are invited to participate in research that will be evaluating Community members and healthcare workers' perceptions and attitudes towards breast milk donation and use of donated human milk in Empangeni, KZN.

This Informed Consent Form has two parts:
• Information Sheet (to share information about the study with you)
• Certificate of Consent (for signatures if you choose to participate)
You will be given a copy of the Informed Consent Form

Part 1: Information Sheet

Introduction

I am Nicole Govender, a dietitian working in Empangeni. I am doing research so that we can understand what caregivers and healthcare staff think and feel about breast milk donation. I am going to give you information and invite you to be part of this research. I am inviting you to take part in a study titled: "Community members and healthcare workers' perceptions and attitudes towards breastmilk donation and use of donated human milk in Empangeni, KwaZulu Natal". You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research. This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me or the research assistant.

Purpose of the research

Breast milk is the best food for babies because it helps babies to grow and to fight infection. Sometimes mothers do not produce enough breast milk to feed their babies after they are born, either because they have an illness or they are under stress. It is possible for breastfeeding women to donate breast milk that can be given to babies who really need it, like ill preterm babies. We currently have a human milk bank at QNRH and we would like to

understand how the community and staff members feel about this. The information will help us to ensure that babies who really need it can receive the donated milk, which will help to improve their chances of survival. You are being invited to take part in this research because we feel that your experience as a community member or healthcare worker can really help us to understand what people in this community believe and feel about the possibility of helping babies to survive by giving them donated breast milk.

Type of Research Intervention

If you agree to take part in this research, you will either be asked to talk to the researcher in a private interview, or in a group with other participants.

Voluntary Participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate all the services you receive at this hospital/ clinic will continue and nothing will change.

OR

The choice that you make will have no bearing on your job or on any work-related evaluations or reports. You may change your mind later and stop participating, even if you agreed earlier.

Procedures

A. We are asking you to help us learn more about donation and use of donor milk in your community. We are inviting you to take part in this research project. If you accept, you will be asked to be involved in an interview or focus group discussion

B.

For interviews

During the interview, I or another interviewer will sit down with you in a comfortable place at QNRH/ Empangeni clinic. We will ensure that the conversation is kept private by sitting in a closed room with no one interrupting us. If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question. No one else but the interviewer will be with you during the interview, unless you would like someone else to be there. If you feel that you need an interpreter, we will arrange that one is present. The information recorded is confidential, and no one else except Nicole Govender

and the research assistant will have access to the information documented during your interview. To help the interviewer understand what you have said she will take notes during the interview and would also like to record the interview so that she can listen to it afterwards. This is so that the researcher can listen to the interview afterward to make sure that everything has been written down correctly. To protect your identity your name will not be on the recording. You will be given a number, and only the researcher will know that information. All the information will be kept safely in a locked cupboard to which only the researcher has access.

For focus group discussions

During the focus group discussion, I or another interviewer will sit down with you in a comfortable place at QNRH/ Empangeni clinic. We will ensure that only the participants of the focus group are present in the room. If you do not wish to answer any of the questions during the discussion, you may say so and the interviewer will move on to the next question. The information recorded is confidential, and no one else except Nicole Govender and the research assistant will have access to the information documented during your interview. To help the interviewer understand what you have said she will take notes during the interview and would also like to record the interview so that she can listen to it afterwards. This is so that the researcher can listen to the interview afterward to make sure that everything has been written down correctly. To protect your identity your name will not be on the recording. You will be given a number, and only the researcher will know that information. All the information will be kept safely in a locked cupboard to which only the researcher has access.

Duration

I will either conduct an interview or focus group discussion with you which will last for about one hour.

Risks

There may not be any direct risks to you for taking part in this research. If you feel that there are any questions you do not want to answer, you are free to do so without consequences. Nothing you say will affect the care you receive at the health facility.

Benefits

However, it may give you the opportunity to think about your own breastfeeding experiences. The most important benefit is that it could help us improve the services we deliver to babies.

Reimbursement

You will not be paid for taking part in this research.

Part 2: Certificate of Consent

I, _____ have been invited to participate in research about human milk donation and use of donor milk which evaluates "Community members and healthcare workers' perceptions and attitudes towards breastmilk donation and use in Empangeni, Kwa Zulu Natal".

I understand the purpose and procedures of the study which includes being interviewed. I have been given an opportunity to ask questions about the study and have had answers to my satisfaction. I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any of the benefits that I usually am entitled to. I have been informed that there is no compensation available. If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher on 084 454 0830 or email address: nicolegovender9@gmail.com If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

If you have concerns about this study, you can contact the following person:

Professor M. Blockman
Chairperson
Health Sciences Research Ethics Committee
University of Cape Town
L51-67 Old Main Building
Groote Schuur Hospital
University of Cape Town
Observatory
Cape Town, 7925

South Africa
Tel +27 21 650 3316
Fax +27 21 650 5203

By signing below, I, _____, agree to take part in a research study titled, "Community members and healthcare workers' perceptions and attitudes towards breastmilk donation and use in Empangeni, Kwa Zulu Natal".

I declare that:

- I have read, or the researcher read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is voluntary and I have not been rushed to take part.
- I may choose to leave the study at any time and will not be penalized or prejudiced in any way.

I may be asked to leave the study before it has finished, if the study researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at _____ on_____ 2019.

Signature of participant (agreeing to participate) _____

Signature of participant (agreeing to interview being audio recorded) _____

Signature of witness _____

Declaration by investigator

I, _____ declare that:

- I explained the information in this document to _____.
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above

- I did/did not use an interpreter.

Signed at _____ on _____2019.

Signature of investigator _____

Signature of witness _____

Declaration by interpreter

I, _____ declare that:

- I assisted the investigator _____ to explain the information in this document to interview using the language medium of IsiZulu.

- We encouraged him/her to ask questions and took adequate time to answer them.

- I conveyed a factually correct version of what was related to me.

- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at _____ on _____2019.

Signature of interpreter _____

Signature of witness _____

Appendix 7

Participant Information Sheet and Consent Form (isiZulu)

Le mvume eyabantu besifazane abakhulelwe kanye nabanakekeli abahlala kulesi sigamu seNkosi uCetshwayo, Kanye nabasebenzi basesibhedlela iQueen Nandi, umtholampilo iEmpangeni Clinic abamenyiwe ukuba bazibandakanye kuloluphenyo mayelana nokuhlolisisa indlela umphakathi Kanye nabasebenzi basemitholampilo ababuka ngayo ukunikela Kanye nokusetshenziswa kobisi lwebele Empangeni, KwaZulu Natal.

Le mvume inezigaba ezimbile:

- Iphepha lemininingwane (ukudlulisa imininingwane yalolu hlungo)
- Isitifiketi semvume (yokushicilela uma uzibandakanya kulolu phenyo)

Uzobe sewuninkwa iphepha elinemvume yakho ephelele

Isigaba sokuqala: imininingwane

Isingeniso

Mina, Nicole Govender, osebenza empangeni, ngenza lolu phenyo ukuzde sizoqondisisa ukuthi ngabe abasebenzi Kanye nabanakekela ngezempilo bacabanga okanye wazizwa kanjani mayelana nokunikelwa Kanye nokusetshenziswa kobisi lwebele. Ngizokunika imininingwane ngiphinde ngikumeme ukube uthathe igxathu kulolu phenyo lwesihloko esithi ‘Indlela umphakathi Kanye nabasebenzi okubuka ngayo ukunikelwa Kanye nokusetshenziswa kobisi lwebele Empangeni, KwaZulu Natal’. Awuphoqelekanga ukuthatha isinqumo sokuba uzibandakanye khona namuhla kulolu phenyo. Ngaphambi kokuzibandakanya, unelungelo lokukhuluma nanoma ubani mayelana nokuthola ulwazi olunzulu. Le mvume izoba namagama okungenzeka ukuthi ungawaqondisisi. Ngicela ungesabi ukungimisa noma ngabe sekuphakathi nemininingwane uma ungasalandeli, ngizokucacisela. Uma unemibuzo ngokuhamba kwesikhathi futhi ungangibuza okanye ubuze omunye wabaphenyi bami.

Injongo yalolu phenyo

Ubisi lwebele lubalulekile kakhulu ezinganeni ngoba luyasiza ukuthi umntwana akhule liphinde lilwe namagciwane. Kuyenzeka ke ukuthi umzali angakhoni ukuba nobisi olwanele ukuba ancelise umntwana wakhe, ngenxa yokugula okanye ukungaphatheki kahle emoyeni nasemqondweni. Kuyenzeka ke manje ukuthi abazali bakwazi ukunikela ngobisi kulabo bantwana abaludingayo, njengabantwana abagulayo Kanye nabazalwe kungakabi isikhathi sabo. Sesinalo ibhange lobisi lwebele esibhedlela eQueen Nandi Hospital kanti sifisa ukuzwa

ukurthi ngabe umphakathi Kanye nabasebenzi bazizwa kanjani mayelana nalokhu. Lokhu kuzosisiza ekuhleleni Kanye nasekelungiseni leli bhange ukuze abantwana abaludingayo lolu bisi bakwazi ukulithola ukuze bakwazi ukusizakala Kanye namathuba okuphila azokwanda. Uyamenywa ukuthatha igxathu kulolu phenyo ngoba sibona sengathi ulwazi lwakho njengowesifazane okhulelwe Kanye nomsebenzi wasemtholampilo lungasisiza ukuqonda ukuthi umphakathi ucabangani futhi uzizwa kanjani mayelana nokusebenzisa lolu hlelo nokuthi izingane zingasizakala kangakanani.

Indlela yophenyo ehlungiwe

Uma uvuma ukuthatha igxathu kulolu phenyo, uzocelwa ukuba ukhulume nomphenyi uqobo okanye ube phakathi kwabanye abazophenywa ukuthola ulwazi.

Ukuzibandakanya ngokuzinikela

Ukubandakanya kwakho lulolu phenyo kungukuzinikela ngokupheleleyo. Uma uzizwa ungaphumeleli ukuzibandakanya, usizo lwase mtholampilo Kanye nasesibhedlela ngeke luphazamiseke.

Okanye

Ukuzibandakanya kwakho ngeke kube namithelela okanye izingqinamba emsebenzini wakho, futhi ngeke kuphazamiseke ukuhlolwa kwakho ngokomsebenzi. Kanjalo futhi uma usufisa ukushiya phansi, ungakwenza lokho noma ngabe ubusuyinikezile imvume.

Indlela

A. Sikucela ukuba usisiza sifunde kabanzi mayelana nokunikelwa Kanye nokusetshenziswa kobisi lwebele emphakathini wakho. Sikumema ukuba uthathe igxathu kulolu hlelo lophenyo. Uma uvuma, uzocelwa ukuba ukhulume nomphenyi umlomo nomlomo, okanye uhlangane nabanye abazophenywa nibe idlanzana ndawonye.

B. **kwabazoxoxa umlomo nomlomo**

Uzobe uhleli nami, okanye omunye wabaphenyi engisebenzisana naye, endaweni enethezekile laphaya esibhedlela eQueen Nandi okanye emtholampilo Empangeni Clinic. Sizoqinisekisa ukuthi ingxoxo yethu iyimfihlo ngokuhlala endlini sivale umnyango ukuze singaphazamiseki. Uma kunomubuzo ofisa ukungawuphenduli, uyasho kanjalo kuzodlulelwa kolandelayo. Kuzobe kuyithi nje sobabili ngaphandle uma ufuna kube khona omunye umuntu. Uma ufuna kube khona ozotolika, nalokho singakulungisa abe khona. Imininingwane ozosinika yona iyimfihlo, akakho noyedwa omunye ngaphandle kuka Nicole Govender ozokwazi ukuyithola.

Uyaziswa ukuthi loyo ozobe ekubuza imibuzo uzobuye alobe phansi ezinye zezimpendulo kanti futhi kuzobe kushicilelwa phansi ukuze kukwazi ukulalelwa ngesikhathi esilandelayo. Lokhu kuzosiza ukuze singashiyi lutho olushoyo. Ukuze sikuvikele, igama lakho ngeke lisetshenziswe ukuqopha. Uzonikwa inombolo ezokwaziwa nguwe Kanye nowophenyo. Yonke imininingwane izogcinwa endaweni ephephile, ivalelwe lapho kwazi khona umnikazi walolu hlelo.

Kwabazohlanganyela ndawonye

Kulabo abazohlangana beyidlanzana, mina okanye omunye kwengisebenzisana naye, uzohlala nani endaweni enethezekile esibhedlela eQueen Nandi Hospital, okanye emtholampilo Empangeni clinic. Sizoqinisekisa ukuthi abazobe bekhona yilabo abazibandakanyile kuphela. Uma ufisa ukugodla umbono wakho ungasho kanjalo ukuze kudlulelwe kolandelayo. Le minininingwane eqhoshiwe iyimfihlo, akekho omunye ngaphandle kuka Nicole Govender ozokwazi ukuyithola. Ukusiza loyo obuzayo ukuthi aqonde kahle, uzobe ebhala phansi izimpendulo kanti futhi inkulumo yonke izobe iqoshiwe ukuze akwazi ukuyilalela ngokuhamba kwesikhathi. Lokhu kuzosiza ukuthi singashiyi lutho olushilo, futhi ukuqopha kuzosiza sikwazi ukulalela ngokuhamba kwesikhathi ukuqinisekisa ukuthi konke okubhaliwe yilokhu okushiwo. Ukuvikela isiqu sakho, igama lakho ngeke lisetshenziswe ukuqopha. Uzonikezwa inombolo kanti umphenyi kuphela ozoba nalolo lwazi. Yonke imininingwane izogcinwa endaweni ephephile, ivalelwe lapho kwazi khona umnikazi walolu hlelo.

Ubude besikhathi

Ngizokhuluma nawe umlomo nomlomo isikhathi esingangehora, okanye uzobandakanya Kanye neningi isikhathi esingangehora.

Ubungozi

Abukho ubungozi kulolu phenyo. Uma kunemibuzo ongathandi ukuyiphendula, unelungelo lokusho kanjalo ngaphandle kwenkinga. Akukho lutho ongalusho olunokuphazamisa ukunakekelwa kwakho kulezi khungo zezempilo.

Inzuzo

Lokhu kuzokinika ithuba lokuzikhumbuza mayelana neyakho imizwa ngokuncelisa. Okubaluleke kakhulu wukuthi kuzosiza thina sikwazi ukuthuthukisa usizo ebantwaneni.

Inkokhelo

Ayikho inkokhelo ezotholakala ngenxa yokubandakanyeka kulolu hlelo.

Isigaba sesibili: isitifiketi semvume

Mina, _____ ngimenyiwe ukuzibandakanya ekuthatheni igxathu ukuhlolisisa mayelana nokunikelwa kanye nokusetshenziswa kobisi lwebele esihlokweni esithi ‘indlela umphakathi kanye nabasebenzi basemitholampilo abayibheka ngayo nabazizwa ngayo mayelana nokunikelwa kanye nokusetshenziswa kobisi lwebele empangeni KwaZulu Natal’.

Ngiyasiqonda isidingo kanye nenqubo yalolu hlelo lophenyo. Nginikeziwe ithuba lokubuza imibuzo kanti nezimpendulo ziyangenelisa. Ngiyaqinisekisa ukuthi ngizinikele ngokuphelele futhi nemvume ngiyinikile. Kanjalo noma ngifisa ukuhoxisa, nginelungelo lokuyeka ngaphandle kokuthikameza usizo engilithola kulezikhungo zezempilo. Ngitsheliwe ukuthi ayikho imiklomelo ezotholakala ngokuzibandakanya kwami. Uma kukhona imibuzo enginayo ngiyazi ukuthiu kumele ngixhumane ngocingo nophenya loluhlelo kulenombolo 084 454 0830 okanye ngithumele ngaloluhlobo ku nicolegovender9@gmail.com. Uma nginemibuzo mayelana namalungelo ami, opkanye ngenqubo yalolu hlelo nokunye, ngingakhona ukuxhumana kanje:

Professor M. Blockman
Chairperson
Health Sciences Research Ethics Committee
University of Cape Town
L51-67 Old Main Building
Groote Schuur Hospital
University of Cape Town
Observatory
Cape Town, 7925
South Africa
Tel +27 21 650 3316
Fax +27 21 650 5203

Ngokushicilela ngezansi, mina, _____, ngiyavuma ukubandakanywa kulolu hlelo lophenyo oluthi ‘indlela umphakathi kanye nabasebenzi bezikhukho zezempilo okubuka ngayo futhi ozizwa ngayo mayelana nokunikelwa kanye nokusetshenziswa kobisi lwebele Empangeni KwaZulu Natal.

Ngiyafunga ukuthi:

- Ngiyifundile okanye ngifundeliwe le minininingwane Kanye nephepha lemvume, futhi konke kubhalwe ngolimi engiluqondisisayo futhi engilwaziyo.
- Nginikeziwe ithuba lokubuza imibuzo kanti futhi nezimpendulo zayo ziyangenelisa.
- Ngiyazi ukuthi ukuzibandakanya akuphoqiwe futhi akekho ongibelesele futhi engigijimisa ukuba mgithathe isinqumo.
- Ngingakhona ukushiya uma ngingasathandi, kantiu futhi ngeke ngisokoliswe ngalokho.

Ngingaphinde ngicelwe ukuhoxa uma umphenyi ebona kufanele okanye uma ngingasenzi ngendlela ebesivumelene ngayo kusaqalwa.

Ishicilelwe e _____ngenyanga ka _____ku 2019

Oshicilele (onikeze imvume) _____

Oshicilele enike imvume yokuqoshwa _____

Ufakazi _____

Isifungo somseshi

Mina, _____ ngiyafunga ukuthi:

- Ngiyinikile imininingwane ekule ncwadi ku _____
- Ngimukhuthazile ukuba abuze imibuzo, ngaphinde ngizinika isikhathi ukuyiphendula
- Nganelisekile ukuthi uyayiqonda yonke imininingwane ekhona la, njengoba ichaziwe ngenhla
- Ngimusebenzisile utolika/ angimusebenzisanga utolika

Ishicilelwe e _____ngenyanga ka _____ku 2019

Umseshi _____

Ufakazi _____

Isifingo sikatolika

Mina, _____ ngiyafunga ukuthi:

- Ngiye ngasiza umseshi ukukubuza _____ukuchaza imininingwane yale ncwadi ngesiZulu

- Sibe sesimukhuthaza ukuba abuze imibuzo, saphinde sazinika isikhathi ukumuphendula
- Ngidlulise lokho obekushiwe kimi njengoba kunjalo
- Ngiyaneliseka ukuthi yonke imininingwane ekhona la iyaqondakala kanti yonke imibuzo yakhe iphendulekile ngokwenelisayo.

Ishicilelwe e_____ ngenyanga ka _____ ku 2019

Utolika _____

Ufakazi _____

Appendix 8

Ethical approval from University of Cape Town

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: sumayah.ariefdien@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

05 November 2018

HREC REF: 590/2018

Dr S Kroon
Department of Neonatology
Room 3.17, 3rd Floor
ICH Building
Red Cross War Memorial Children's Hospital

Dear Dr Kroon

PROJECT TITLE: COMMUNITY MEMBERS AND HEALTHCARE WORKERS' PERCEPTIONS AND ATTITUDES TOWARDS BREASTMILK DONATION AND USE IN EMPANGENI, KWA ZULU NATAL (MPhil Candidate - Miss N. Govender)

Thank you for your response, addressing the issues raised by the Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 November 2019.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the student: Miss Nicole Govender will also be involved in this study.

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

Signature Removed

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.

Appendix 9

Permission letter to conduct research from QNRH

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

DIRECTORATE:
QUEEN NANDI REGIONAL HOSPITAL

29 Union Street, EMPANGENI, 3880
Private Bag X20005, EMPANGENI, 3880
Tel: 035 907 7221 Email: Lowerumfolozi.paeds@kznhealth.gov.za
www.kznhealth.gov.za

29 November 2018

To. Nicole Govender

RE: PERMISSION TO CONDUCT RESEARCH AT QUEEN NANDI REGIONAL HOSPITAL

Dear Madam

I have pleasure in informing you that permission has been granted to you by the Queen Nandi Regional Hospital Ethics Committee to conduct research on " **Community members and healthcare workers perception and attitudes towards breastmilk donation and use in Empangeni, Kwa Zulu Natal.** "

Please note the following:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.
3. Please ensure this office is informed before you commence your research.
4. Queen Nandi Regional Hospital will not provide any resources for this research.
5. You will be expected to provide feedback on your findings to our Institution.

Sincerely

Signature Removed

Dr I Popa
Chairperson
Ethics Committee

Approved by:

Signature Removed

Mrs CNN Mkhwanazi
Chief Executive Officer QNRH

Appendix 10

Permission letter to conduct research from Ngwelezane hospital

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

DIRECTORATE:
Office of the CEO
Ngwelezana Tertiary Hospital

Ngwelezana Hospital, Thanduyise Road, Ngwelezana Township
Private Bag X 20021, Empangeni 3880
Tel: 035 901 7000 Fax: 035 794 1883 Email: ceosecretary.ngwelezana@kznhealth.gov.za
www.kznhealth.gov.za

Enquiries: Ms. N. Sibiya
Date : 03 December 2018

Dear Ms N Govender

PERMISSION TO CONDUCT RESEARCH ON COMMUNITY MEMBERS AND HEALTHCARE WORKERS PERCEPTIONS AND ATTITUDES TOWARDS BREASTMILK DONATIONS AND USE IN EMPANGENI, KWAZULU NATAL

I have pleasure in informing you that permission has been granted to you by Ngwelezana Hospital to conduct research on: ***"Community members and healthcare workers perceptions and attitudes towards breastmilk donations and use in Empangeni, KwaZulu Natal.***

Please note the following:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. Please ensure that the office of the Clinic Operational Manager is informed before you commence your research.
3. The District Office/Facility will not provide any resources for this research.
4. You will be expected to provide feedback on your findings to the District office/Facility.

Thanking you.

Sincerely

Signature Removed

Dr BS Madlala
Chief Executive Officer
Ngwelezana Hospital

Appendix 11

Reciprocity to the University of Cape Town's Health Research Ethics Committee from University of KwaZulu- Natal

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI
RESEARCH OFFICE
BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 260-4609
Email: BREC@ukzn.ac.za
Website: http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx

26 November 2018

Ms N Govender
Department of Pediatrics and Child Health
University of Cape Town
South Africa
nicolegovender9@gmail.com

Dear Ms Govender

Protocol: Community members and healthcare workers perceptions and attitudes towards breastmilk donation and use in Empangeni, KwaZulu-Natal.
Degree: MPhil (MCH) **BREC REF NO.: RECIP671/18**

I wish to advise that your request received on 08 November 2018 has been considered by the Chair of the Biomedical Research Ethics Committee (BREC).

The chair has granted reciprocity to the University of Cape Town's registered Health Research Ethics Committee (HREC) approval (HREC 590/2018) dated 05 November 2018.

This approval will be noted at the next Biomedical Research Ethics Committee meeting to be held on 11 December 2018.

Yours sincerely

Signature Removed

Prof V Rambiritch
Chair: Biomedical Research Ethics Committee

Supervisor: Dr M Kroon (Max.kroon@westerncape.gov.za)
Co Supervisor: Dr P Reimers (pennyreimers@outlook.com)

Appendix 12

Approval to conduct research from KZN DoH

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

DIRECTORATE:
Health Research & Knowledge Management

Physical Address: 330 Langalibalele Street, Pietermaritburg
Postal Address: Private Bag X9051
Tel: 033 395 2805/ 3189/ 3123 Fax: 033 394 3782
Email:
www.kznhealth.gov.za

NHRD Ref: KZ_201812_010

Dear Ms N. Govender
University of Cape Town

Approval of research

1. The research proposal titled **'Community members and healthcare workers' perceptions and attitudes towards breastmilk donation and use in Empangeni, KZN'** was reviewed by the KwaZulu-Natal Department of Health.

   The proposal is hereby **approved** for research to be undertaken at Queen Nandi Hospital and Empangeni Clinic

2. You are requested to take note of the following:
   a. Kindly liaise with the facility manager BEFORE your research begins in order to ensure that conditions in the facility are conducive to the conduct of your research. These include, but are not limited to, an assurance that the numbers of patients attending the facility are sufficient to support your sample size requirements, and that the space and physical infrastructure of the facility can accommodate the research team and any additional equipment required for the research.
   b. Please ensure that you provide your letter of ethics re-certification to this unit, when the current approval expires.
   c. Provide an interim progress report and final report (electronic and hard copies) when your research is complete to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

Signature Removed

Dr E Lutge

Chairperson, Health Research Committee

Date: 12/12/18

Fighting Disease, Fighting Poverty, Giving Hope